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ABSTRACT

The book reviews trends and developments in residential services for mentally handicapped persons. The first section deals with basic changes in the number of institutionalized residents (including detailed statistics on numbers and costs per patient for each state), the origin and nature of institutionalized models (architectural and historical influences), and the experiences of a mother of a handicapped child. Reviewed in the second section are the roles of the public (including the news media), the government, and foundations in changing residential services. The focus of a fourth chapter is on changing patterns, including a discussion of the normalization principle, and examples of innovative national, provincial, and local patterns. Implications of changing services on building design, residential staffs, parents, and communities such as L'Arche are analyzed in a fifth section. (CL)

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Changing Patterns in Residential Services for the Mentally Retarded

Revised Edition

BEST COPY AVAILABLE

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President's Committee on Mental Retardation
Washington, D.C. 20201
1976

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Preface

Considerable progress has been made in residential services for the mentally retarded since the President's Committee on Mental Retardation, in 1969, published the first *Changing Patterns in Residential Services for the Mentally Retarded.* No single report so profoundly affected thinking in the field of mental retardation as did this monograph. The internationally known authors presented challenging new service concepts, that spread rapidly. Over 20,000 copies of the 1969 monograph have been distributed throughout the world. Several countries translated it into their own language, and the President's Committee still answers requests for information and copies.

Change has been so rapid that we need once again to examine our situation, the new challenges and the emerging service models. The Federal Government has focused attention on this major issue and States have developed deinstitutionalization plans which emphasize new alternatives in community service programs. This has further developed reform within our public institutions by reducing their size and providing means for evaluation and placement of their residents in a less restrictive environment.

Normalization, a term popularized by the 1969 report, has been a guiding principle for planners in establishing standards of services.

The President's Committee on Mental Retardation is indebted to Dr. Robert B. Kugel and Ann Shearer, the editors of this new edition, and the contributing authors. Retaining the values of the original monograph while adding much important new material, they have provided the imaginative, people-related thinking which must underly improvements in services to the Nation's millions of mentally retarded persons.

In spite of progress made since the first edition, we still have a number of institutions in the United States which are overcrowded, understaffed and poorly financed. And there remain many gaps in quantity and quality of community-based services. But with the emerging Federal, State and local programs we hope that by the end of this decade many of these problems will be on the way to solution. The President's Committee on Mental Retardation is dedicated to that end, and presents these papers not as the official position of the PCMR but as views of the authors that can contribute to further beneficial change in the pattern of residential services.

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Part I: Introduction

Introduction

Robert Kugel

There is little in human affairs which can be said to be static. Fortunately, new concepts in the residential care of mentally retarded people have continued to develop since the first edition of this book in 1969. This second edition includes some material updated from the first edition but it also contains new points of view and new information which I hope will stimulate thought, debate and further change.

During 1966 and 1967, when I had an opportunity to review residential services for retarded people, both in this country and in other countries, I was struck by two things. First, it was clear that there was no national plan or pattern for change in the United States. All states seemed committed to the continuation of some type of fairly large residential facility for retarded persons even though there were sharp differences of opinion about what the program objectives should be in the residential facility. Second, in those places where more extensive community-based programs had been developed, such as in Connecticut and in the Scandinavian countries, I found it difficult to ascertain how these changes had really come about, despite repeatedly asking the question of the leaders who were operating the programs.

When I again contacted many of the same people in 1973 and 1974, I asked the same questions and this time many more had reflected on how change had come about and had reviewed what the factors were which had contributed to that change. Because I have been repeatedly asked this question and because we hope the answers may be helpful in stimulating further change, we are devoting a section of this book to exploring this issue in considerable detail. Individuals concerned with social change might well find parallels in what has occurred in the thinking about mental retardation.

As I have reviewed the comments of many people, I am struck by the importance of having, first of all, a group of people who are convinced that the present status does not answer the needs of them or their children. The history of the parent movement throughout the world has been an extraordinary example of how individuals with a similar problem coming together and developing a common objective simply cannot be denied, even though the particular group they represent may be a small minority.

However, no group is effective until they gather some additional momentum. This momentum has often come in large measure from various types of mass media: the press, radio, television. Each of these media has played a particular part by portraying to a larger group of people the inadequacies or the inefficiencies of a particular program. Until still more people are convinced, no change will take place. The concerns voiced by rank and file citizens and amplified through the media finally reach governmental bodies. Governmental process is a complicated one, involving the executive arm of government as well as the legislative. After consultation, programs are reviewed, priorities are established, and new efforts are forged as a result of the interaction among the legislative and executive branches of the government and various citizen groups.

The third arm of government, the judicial branch, has been utilized in the United States in a way which seems to have had no parallel elsewhere in the world. Failing to receive sufficient attention through either of the other branches of government, parent groups and other advocates have sought judicial action, which has caused some extraordinary repercussions throughout the country. The utilization of the judicial process was not anticipated by most students of the mental retardation scene, but has now become an important part of how change has occurred in the United States.

To varying degrees, other large organizations have had important roles in bringing about changes in residential services for retarded persons. American universities have responded with both research and training.

Research efforts related to the etiology of mental retardation have served to improve our understanding of various aspects of it. Other studies have been directed to the assessment of various treatment programs for the ratarded. The university-affiliated centers for the study and treatment of mental retardation and related disorders have been an important force in research, although not as strong as some would like.

In addition, universities have responded to changing program needs by providing education for individuals who will care for retarded persons. Such efforts, while sporadic, have had important implications in many instances. Probably the best example would be in special education. As the result of the work of colleges and universities, the number of trained teachers now almost meets the demand.

Some private foundations have utilized their resources and prestige in a variety of ways to stimulate thinking and to produce change on behalf of mentally retarded people. While such foundations are not found throughout the world, two will be mentioned here because of pertinent contributions—the Joseph P. Kennedy, Jr. Foundation in the United States and King Edward's Hospital Fund for London.

Finally, we have included chapters on two sets of people whose contributions to change are perhaps not dramatic or easily documented but are nevertheless important to consider if we are to understand the process of change. These are the mentally handicapped people themselves and the staff who care for them. These are the people, after all, at the center of the patterns of which others, more distant, are framing the outlines. It is they who will have to live with the changes and who can make important—if as yet largely untapped—contributions to the way the outlines of care come alive.

In trying to analyze how social change has come about, it has occurred to me that one of the important parts of any society is its religious institutions. In looking at the church, both in the organized and the diffuse sense of the word, it is of interest to note that while in many situations the church has been a leader in producing change, this has not been so in the case of retardation in the U.S. I will leave for others the more searching analysis of why this should be.

I rather doubt that there is a single "recipe for change," although I think it is important to note that we need most of the ingredients listed if significant change is to take place.

The importance of periodically examining the tenets of our society has been attested to over and over again. Unfortunately, ideas have a way of languishing if there are not the financial means of turning them into action. Columbus could not try out his idea about the roundness of the world without the support of Ferdinand and Isabella of Spain, and the astronauts could not have reached the moon without a generous Congress of the United States. In the same way, changes in residential services for retarded persons, very likely, would not have occurred had it not been for a level of prosperity which permitted the translation of ideas into practice. But now there is a worldwide economic pinch which will cause people again to review priorities to determine how scarce funds will be allocated.

As a consequence, the same question will again need to be asked. Will there be institutions as we have known them in the past? If so, how large will these institutions be? Is it possible to replace all of the residential facilities with community-based programs? Is it desirable to move in that direction? The section on "Patterns Which are Changing" offers different experiences of care which we hope will stimulate thought on these questions.

The Problems

For the purposes of this volume, residential services will refer to any situation where an individual is not in his own home at all or where at least five days a week are spent outside of the individual's home. Under this definition, there can be a wide variety of residential services. Such services would certainly include the traditional, multipurpose residential facility where individuals spend the entire week. But it may also mean a crisis assistance unit where an individual might spend one or two weeks. It would also include programs designed for a five-day week where the individual returns regularly to his own home over the weekend, for holidays, and for vacations, as in boarding schools.

I believe, as many others do, that we should plan now to phase out all of the large residential facilities, replacing them with a variety of community-based programs and services. The five-county area in Eastern Nebraska, known as ENCOR and described elsewhere in this book, is one such attempt to accomplish this objective, although that service program is not yet complete in all respects. If one is to give serious credence to such an aim, however, much more extensive planning and implementation must be undertaken.

Certain individuals, by virtue of the complexity and severity of their problems, need to be singled out for special consideration. These special groups will include the retarded person with objectionable or difficult behavior, the retarded person with severe physical disabilities (blindness, deafness, or cerebral palsy), the retarded person who has been judged to have committed some crime or misdemeanor, and the retarded person who comes from a family where poverty has been an important factor in the life of the family. I will consider each of these groups separately.

1. The Retarded Person With Objectionable or Difficult Behavior

Many professional authorities simply do not agree about the meaning and significance of certain manifest behavior. Professionals may debate whether, in a given individual, the mental retardation or the emotional disturbance is dominant or primary and which problem should be considered first. However, the people who must care for the individuals with both retardation and emotional disturbance, such as attendants in our present institutions or the teachers in the classroom, have no doubt that behavior which is destructive, aggressive or disruptive may well make it impossible for the individual to be contained in the usual type of setting, such as the child's own home, a community-based school or a day room with ten or more people in it.

Another concern is about autism. Some authorities consider this disorder to be reversible and transient; others regard it is a variety of mental retardation which has an undetermined biological component, is not reversible, and is only minimally likely to respond to treatment. People generally agree, however, that individuals regarded as "autistic." are very difficult to manage. Their periodic and violent emotional outbursts and their extreme behavioral aberrations, such as twirling and headbanging, make them difficult to contain in the usual community setting.

Although it is agreed that the problems of individuals with extreme behavioral aberrations pose great problems in care wherever they are, those who indicate that all people now in the large residential institutions can be returned to the community have the burden of proof to devise community programs capable of meeting the needs of these very difficult individuals. New techniques such as conditioning or behavioral shaping offer some promise here. The chapter in Part IV on the Wessex program of hostels in England considers the problem in some detail.

There is significant evidence to suggest that certain objectionable behavior, such as biting, kicking, aimless running, and short attention span, is aggravated in an institution with a constantly changing staff with indifferent attitudes about the worth of the individual. Attempting to place these individuals back in the community poses some very grave problems. The ability to cope with them has often been lacking, and some leaders dedicated to community-based programs have simply not provided in their plans for people with severe and extensive disruptive behavior.

2. The Retarded Person With Severe Physical Impairment

In the past, the individual with severe cerebral palsy would often spend most of his life in a residential facility, as would the person with retardation and some combination of deafness and blindness. Many cerebral palsied children were placed in institutions where minimal help was provided for them. Although many individuals with severe cerebral palsy do have significant amounts of retardation, others clearly do not. There can be no justification for including both retarded and nonretarded cerebral palsied children in programs that are designed solely for those who are retarded and have only minimal provisions for those children with normal or near normal intelligence. Tragedies continue to occur where no attempt is made to work out solutions within the community for these physically disabled individuals. Their disabilities usually can be managed, and many examples exist where such persons have been accommodated successfully when there is a full range of a community-based programs.

Individuals with other special problems, such as the combination of blindness, deafness, and degrees of retardation, present somewhat greater difficulties. More programs are now emerging which do accommodate these individuals in the community. Bengt Nirje, in his contribution, explores what normalization means to deaf retarded people. A combination of community-based residential facility, day-care programs, vocational training, and special education may be required to meet their needs. Attempting to accommodate these individuals in smaller communities poses still other problems. Great skill and ingenuity is required of those charged with planning and implementing comprehensive community programs if solutions are to be found.

3. The Mentally Retarded Criminal

Although it may be harsh to use the word "criminal" in connection with many mentally retarded people, nonetheless, we must not shy away from it. Our society has a series of laws and a system for enforcing these laws which must be kept in mind when planning community-based programs. In the past, many individuals who have come into conflict with the law and who have some degree of retardation were quickly sent to an institution for retarded persons rather than to a penal institution. Such individuals had, in effect, no trial and no sentence. Consequently, some of them were condemned to what has been described as an indeterminate sentence, under which they might be confined most of their life for a relatively minor misdemeanor.[1] One problem which has often caused particular trouble is sexual acting-out, even such a minor offense as that of the peeping tom. Society frequently exhibits little sympathy for the adolescent generally, and the adolescent who is mentally retarded and sexually acting-out has had even greater problems in finding understanding and acceptance in the community. Because many of these people proved to be capable workers once they were in the institution, little or no effort was made to return them to the community. They simply were too valuable to the institution and this gave rise to the special problem of institutional peonage.

Some statistics would suggest that 10 percent of all individuals in our penal institutions are mentally retarded. The factual basis for such a statement is difficult to substantiate, but even if only five percent of all individuals in penal institutions are mentally retarded, this is a sizeable number and one which has been looked at very little in considering community-based programs for the retarded. In thinking about mentally retarded persons in institutions, most people have ignored the fact that some of them are in an institution of another sort—the penal institution. Yet if one is to provide for all mentally retarded persons while adhering to the concept of community-based programs, this group, difficult though they are, must also have their needs met. Planning for their rehabilitation will take ingenuity.

Still other questions must be reviewed. Should the mentally retarded person be asked to stand trial in the same manner as other individuals? One small but difficult group is made up of people sometimes called "defective delinquents" or "sociopathic delinquents." These individuals are characteristically mildly retarded, and their behavior brings them into conflict with the law over and over again. Apparently, they retain little from past experience about what constitutes acceptable behavior in the eyes of the majority of the people. When taken into custody, these individuals tend to fall into a jurisdictional morass, claimed by no one. Psychiatric authorities tend to give up on them, educators feel harassed because the misbehavior becomes increasingly disruptive, and social workers find them too complicated. Institutional placement seems the only alternative available. The managers of the institutions understand well the series of failures which brought the person to them but they are frequently unwilling or unable to offer much in the way of a rehabilitative effort for these social misfits.

4. The Mentally Retarded Person From A Background Of Poverty

Although there is no agreement on the exact percentage of retarded individuals whose retardation is in large measure due to the pernicious combination of family and community circumstances related to poverty, most authorities in the United States would argue that it is substantial. They may well constitute 50 or 60 percent of the total number of retarded people. While in the United States most people would still hold that three percent of the total population are mentally retarded, studies done in other countries do not corroborate this figure. In Sweden and Denmark, the figure of one and one-half percent is used. The difference is generally attributed to the large group of people in the United States who come from backgrounds of social and economic deprivation. I have written about one such group of individuals in *Children of Deprivation*.[2] An extensive review of the whole subject has been made by Hurley.[3] These individuals characteristically come from families where at least one member of the family is regarded as mentally retarded and where no biological basis for the retardation can be ascertained on the basis of present methods of diagnosis. They are almost always regarded as mildly retarded. They make up a large part of the special education classes in our cities, and are also numerous in rural areas, although their numbers and whereabouts are often poorly understood and appreciated. Many such individuals are still found in the large state-run residential institutions.

In trying to place these persons in the community, it becomes painfully obvious that the community often does not wish to have them return but believes it better for them to be out of the way. Furthermore, when one talks about returning some of them to a family, one recognizes that many of them have no family. Foster home care is not a feasible alternative in the case of many of these children because of lack of funds or of sufficient foster homes of the caliber needed. Unless efforts to mitigate against the deleterious effects of poverty are broadened, this group if individuals will continue to be present in large numbers in state residential facilities.

The study which has been described in *Children of Deprivation*[4] offers one solution. The children and their families were served by a varied group of professional people, among them social workers, psychologists, educators, physicians, nurses, and home economists. These professionals helped both children and families in a coordinated way with their many problems, and most significantly, did so while keeping the children in their own home.

Staffing and Costs

In 1967 I said that institutions for mentally retarded persons were plagued by the triple problem of overcrowding, understaffing, and underfinancing. While I believe that this was an accurate way to state the case on the basis of all of the evidence then available, I think this is not true for 1975. The numbers of individuals in institutions for the retarded have declined in many places so that the extreme of overcrowding is no longer present. In their zeal to accommodate to the generally held opinion that there are too many people in the multipurpose institution, some superintendents have returned clients to community-based programs or other residential programs such as rest homes, county homes, nursing homes, and the like, where the care offered the retarded person may be inappropriate and is sometimes worse than that which he had been receiving in the institution. It becomes important to be certain that the changes which are made move the retarded person in a direction of greater self-sufficiency—a more normal existence.

The issues related to staffing and costs need to be reviewed carefully. A large element of cost in any institution is borne by personnel required to operate a laundry, a food service program, and the multiple staffing necessary to maintain a 24-hour program. In planning for the future, questions must be raised as to whether the amount of money available is insufficient or whether the money now available is being used in the wisest fashion. I would argue that reallocation of some institutional funds to community-based programs would both provide savings overall and offer a more appropriate service to retarded people.

On the other hand, the budgets of many institutions still appear inadequate to meet certain specialized needs, such as physical therapy, occupational therapy, special education, speech therapy, etc. If we are going to continue to use these residential facilities during the transition towards community-based programs, then it becomes incumbent upon everyone to make certain that the tasks which are set before the staff of the residential facility can actually be carried out. To do so will require more money.

Solutions

I have taken the basic position that the ultimate solution is to provide in the community those specialized residential services which may be deemed necessary for retarded people. The institution of the past, consisting of 500, 1,000, 2,000, and even 5,000 individuals, is an anachronism. We will need, however, to exercise far greater ingenuity than we have in the past in providing for these special needs.

The concept of normalization is, I believe, much easier to understand than to accept. In Chapter 15, N.E. Bank-Mikkelsen writes pointedly about the importance of attitude. He states that if concerned groups (parents, families, and professional workers) are to convince the public and legislators that retarded persons do have rights and that these rights should be guaranteed and provided in community-based programs, then they must communicate effectively the opinion and experience which will lead to attitudinal changes.

These changes must occur among those who have no particular commitment to retarded persons, but who do have a commitment to seeing that services, programs, and provisions are available to all individuals, whatever their station or situation in life. As this attitude becomes more general, then to suggest that the residential institution of yesterday will disappear tomorrow seems a well-founded boldness. There are now sufficient examples around the world and in this country to demonstrate that it is possible to meet the needs of individuals with special problems in the community. For the next decade, the task will be one of informing and convincing more and more people about what has been accomplished. It seems appropriate to point out that this book deals with patterns which are still changing. The present situation is far from static, and it may be that the proposals and programs which have been started and which show great promise may need to be modified in the light of additional experience.

In attempting any major social change, no one should be surprised if the first attempts are not completely successful. If the attitude is one of commitment to solving problems in the communities, then there should be no fear about lack of ingenuity in meeting complex social problems. The technique of segregating individuals or groups away from the mainstream of society has always been a defeatist one, based on the premise that people cannot work together to solve common problems in their own communities.

It will be argued that some of the statements in this chapter, as well as in other chapters, are idealistic and impractical. I would suggest, however, that no major social reform was ever accomplished without first striking a note of idealism. The American Declaration of Independence and the concept of universal education would be two such obvious examples.

During the past six or seven years, many programs have been developed which demonstrate the validity of applying the normalization principle for many more retarded people than ever before. While this success should spur us on to try to include all retarded people within the concept of normalization, the fact remains that the special needs for the difficult-to-manage groups mentioned have not yet been met. Unless we try to include all, the boast will be hollow. The challenge is clearly at hand!

Finally, a word of explanation about the range of contributions to this volume. In today's world, which recognizes an increasing interdependence, it becomes important to take advantage of experiences and knowledge in one place which may be helpful and appropriate in another. Therefore, non-American situations are important and should be reported.

Many times, individuals in the United States have remarked that countries like Denmark and Sweden, with their small and homogeneous populations, are so different from the United States, with its much larger population and far greater degree of heterogeneity. It does seem appropriate, however, to think of these countries, with their approximate populations of 4½ million and 8 million, respectively, as being similar to many of our states in population, geographic size, etc. For example, the State of Minnesota is the approximate geographic size of Denmark and has approximately the same number of people. The ethnic background is similar as well. When one sees these countries in this light, then the type of experiences which they have had and the programs which seem to have been successful are worth comparing with situations in the U.S.

To all of the collaborators in this volume, we extend our special thanks. Each person has willingly given of his efforts to make this volume what it is. We do not make any claim that this volume represents an exhaustive treatise on the subject of residential services. Rather, we suggest that these contributors give representative points of view and provide some special insight into certain aspects of residential services as the authors have experienced and understood the situation. We have not asked that the authors conform to any one style or one approach. Each individual reflects his own style.

Special thanks are also due to Judy Nelson for much patience and hard work in typing the different drafts of these manuscripts.

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Biography

ROBERT B. KUGEL was born in Chicago in 1923. He received his B.A. and M.D. degrees from the University of Michigan and took advanced training at the University of Michigan Hospital and at the Yale University Child Study Center. After spending two years in England as a member of the United States Air Force, he directed the Division of Child Health of the Baltimore City Health Department and, later, the Child Development Clinic at the University of Iowa Hospital.

In 1965, he became director of the Child Health and Development Center at Brown University. Subsequently, he was director of the Growth and Development Institute, chairman of the Department of Pediatrics and Dean of the College of Medicine at the University of Nebraska Medical Center in Omaha, Nebraska.

Dr. Kugel was a member of the President's Committee on Mental Retardation and chairman of its subcommittee on the state of the nation.

Dr. Kugel is currently Executive Vice Chancellor of the University of Kansas Medical Center, Kansas City, Kansas, and Professor of Pediatrics.

Residents Speak Out

"They asked me if I enjoyed being called a resident and I told them I'd always been a resident, as far as I'm concerned whatever you say won't make any difference. We'll still be patients here, won't we? It doesn't make any difference, does it? It would be nice to be called a resident if I went somewhere else."

"Being in the institution was bad. I got tied up and locked up. I didn't have any clothes of my own and no privacy. We got beat at times but that wasn't the worst. The real pain came from always being a group. I was never a person. I was part of a group to eat, sleep and everything. As a kid I couldn't figure out who I was. I was part of a group. It was sad."

"You can go into a hostel and be hospitalised if you're in a hostel. No freedom— like a little animal or dog. If they say you got to go to bed you've got to go, you can't go on your own. You can't choose. You got no life of your own, you're not independent or anything. You come in and they take it all away."

"I know I keep the boundaries— I don't smoke, I don't drink, I'm allowed to go out at night, I go to church on my own. But I have to come back, don't I, worse luck? There's no alternative, where are you going to go?"

"I have one goal. People should not have to spend their lives in an institution! It's a long hard fight and we can't do it alone."

"All people are created equal and have the right to live as well as others in the community and fight for rights."

"Don't tell them a resident told you. The resident'll get into trouble. We're not supposed to be so smart; we're not supposed to know everything. They think we haven't got enough sense to know. You'd think after they got to know us— but I've been living here for four years— they don't know me yet."

"I've been here four years and two months. They don't talk to me. They don't know I'm around. They don't know me at all."

"I've been living here 5 years, going on 6. Be 6 years the 14th of this month. You just haven't lived here, so you don't really know."

Comments by mentally handicapped people taken from *Our Life*, Campaign for the Mentally Handicapped, London (1972); *Listen*, CMH, London (1973); *Where do we go from here?*, Youth Massachusetts Association for Retarded Citizens (1974); *Listen! Let us speak* in *New Neighbors*, P.C.M.R., Washington, D.C. (1974).

Part II: Starting Points

2. Some Basic Changes in Residential Facilities

Earl Butterfield

National Trends

Much about residential facilities for mentally retarded persons has changed since 1969, when the first edition of this monograph appeared. We can see now what we could not see then: 1967 was a watershed year. Until then, the number of residents in public facilities for the mentally retarded had increased steadily. Since 1967, the number has decreased. These trends are shown in Figure 1.

Information about number of residents in public institutions was collected for the first time in 1950. In that year, there were 128,145 residents in U.S. public facilities. The next year for which the data are available is 1955, and similar information has been published for every year since then until 1971. Figure I shows that between 1955 and 1967 the number of residents in this nation's public institutions increased from 143,548 to 193,188. Every one of these 12 years saw more mentally retarded people in residence. Every year

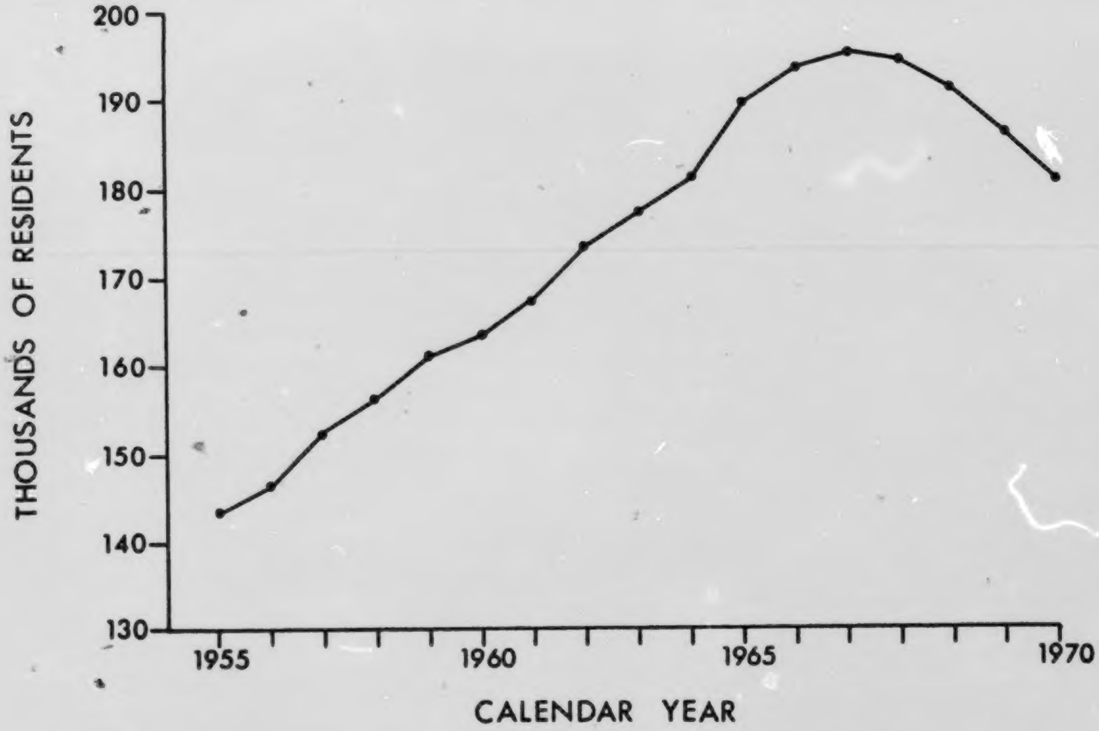

Figure 1. Number of residents in public institutions for the mentally retarded from 1955 to 1971.

thereafter, fewer have resided in our public institutions. The number dropped from its 1967 zenith to 181,058 in 1971. Official statistics are not available to confirm that this trend has continued until today, but direct inquiry has shown me that many public facilities have decreased their census even further since 1971.

The downward trend in institutional census is not the result of the actions of a few states. It is a strong national direction. Thirty-one of the 50 states decreased their residential populations during each of the years between 1967 and 1971. Nineteen of these began their downward trend before 1965. Only 11 states had not begun to decrease by 1970. New Jersey was the only one of these 11 from outside the South. The southern states have regularly lagged behind our nation's trends in caring for its sick and disabled citizens. History will catch up with these states, and they too will decrease their residential roles.

The historic reversal in the number of our institutionalized mentally retarded people is due to one factor only we are releasing more residents to live in other settings. Figure 2 makes this clear.

Our nation's public facilities are admitting as many residents as they ever have. Between 1955 and 1965 there was a steady increase in the number of people admitted to institutions for the mentally retarded. From 1966 on, the number admitted each year was almost constant. The decrease in residential census is not the result of a decrease in admissions. Neither is it the result of increased deaths. The number of deaths among institutionalized mentally retarded people did not change appreciably from 1955 to 1971. There are fewer residents in public facilities for the mentally retarded because increasing numbers have been released. Figure II shows a dramatic upturn in the rate of release from public institutions beginning in 1965. By 1971, more people were released than were admitted.

The residents who are being released in greater numbers from public facilities for the mentally

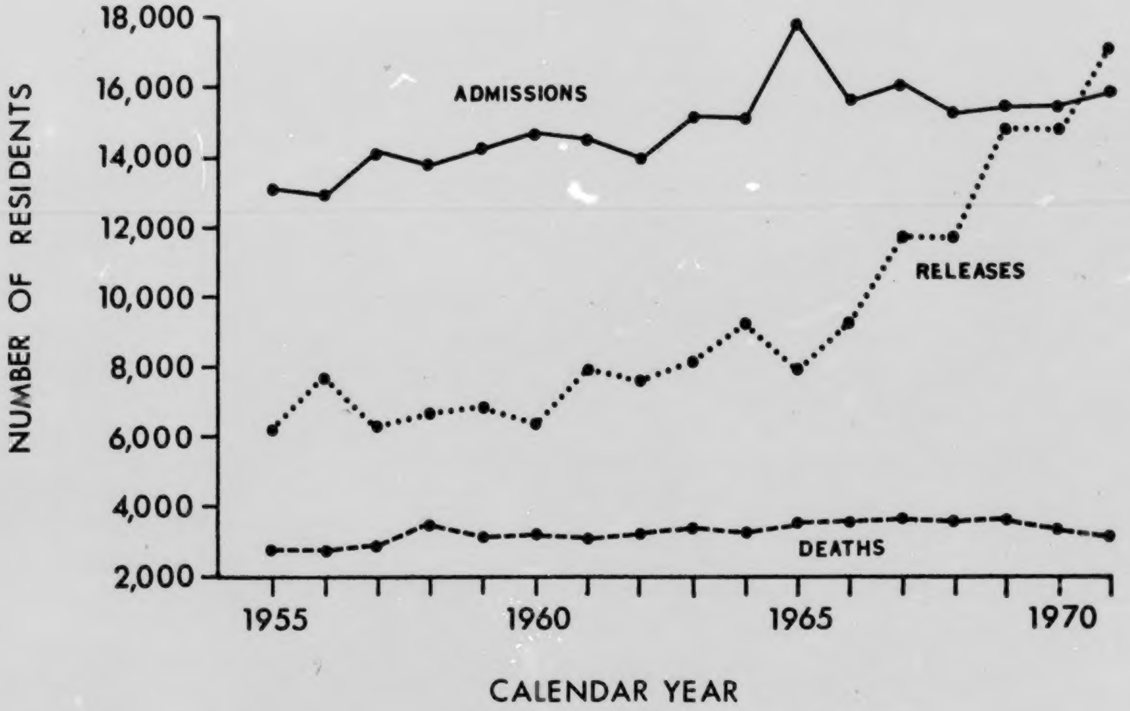

Figure 2. Number of people who were admitted to, released from or died in public institutions for the mentally retarded from 1955 to 1971.

retarded are apparently not going to other institutions. Table 1 shows a steady decline since 1950 in the number of mentally retarded residents housed in public psychiatric facilities. In 1971, there were only two-thirds as many retarded residents in public mental hospitals as there were in 1950. The data are less complete from private institutions for the mentally retarded but they show a downward trend too. Between 1969 and 1970 the number of residents in private facilities for the retarded decreased 14 percent. Private mental hospitals have never housed enough mentally retarded residents to count in any national trend. Data from prisons are scanty but they suggest that the number of incarcerated mentally retarded people has not increased substantially in recent years. The released retarded people are evidently living in community arrangements that are more normal than institutions.

Why are more retarded people now being released from residential facilities? Have our states decided that residential placement is not appropriate for mentally retarded people? The fact that admissions have stayed high seems to rule out this explanation. Have the states decided that they must reduce the costs of maintaining residential facilities? Figure 3 suggests that they have not. It shows that new public residential facilities for the mentally retarded have been constructed almost as rapidly since 1967 as before. In 1971, there were 190 public institutions for the mentally retarded in this country, which was an increase of 25 over the four years from 1967. Thirty new public facilities were opened in the four years between 1962 and

TABLE 1

Number of Mentally Retarded People in Residential Arrangements Other Than Public Mental Retardation Facilities

Year	Public Mental Hospitals	Private Retardation Facilities	Private Mental Hospitals	State & Federal Prisons
1950	48,226			
1955	47,620			
1960	43,486			
1965	35,727			
1968			86	13,400
1969		26,162	75	
1970	30,327	22,014		14,000
1971	29,272			

1966. The number of full-time employees of public institutions has continued to increase as rapidly as in earlier times. Their number grew from 94,900 in 1967 to 118,909 in 1971, an increase of 24,009. The increase was 25,256 from 1962 to 1966. The combined maintenance budget of our 190 public institutions exceeded one billion dollars for the first time in 1971: it was $1,002,557,588. During 1967, it was $576,620,954. The increase from 1967 to 1971 was thus $425,936,634. Between 1962 and 1966, the increase in maintenance budgets was $181,070,167: this is less than half the increase between 1967 and 1971.

Increases in the number of institutions, the number of employees working in them and in institutional operating budgets suggest that the states are not trying to reduce the cost of providing residential services for mentally retarded people. On the contrary, one might conclude that the states had mounted an expensive effort to improve their residential facilities. Figure 4 provides some evidence in favor of this interpretation.

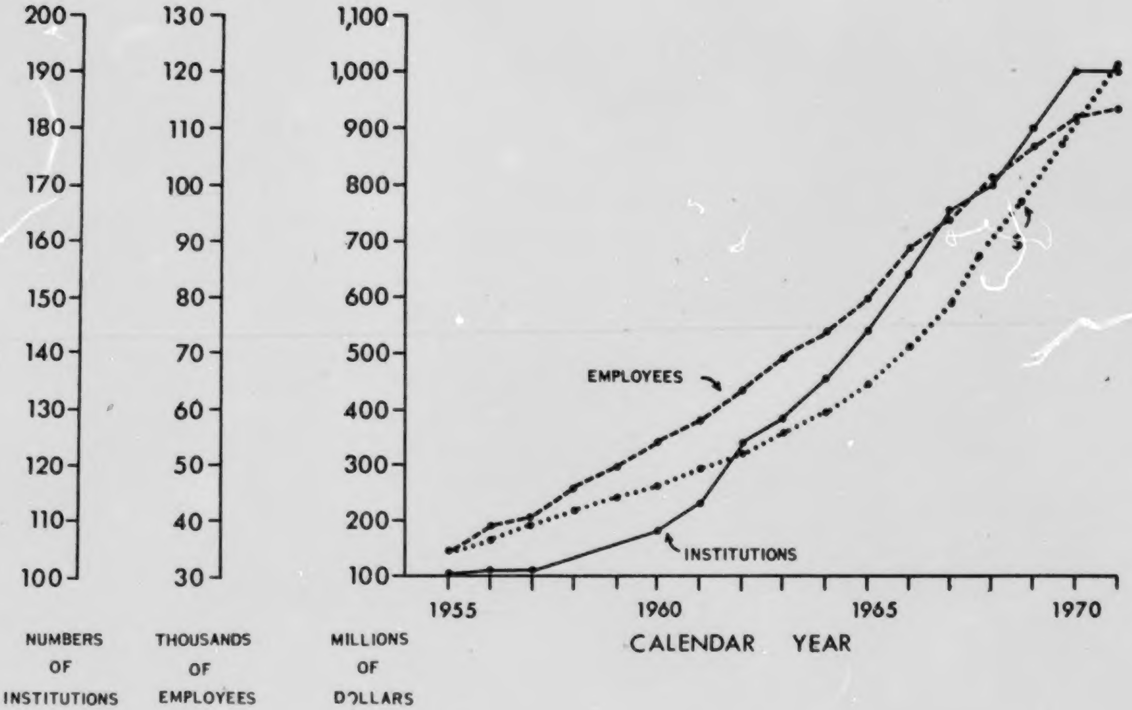

Figure 3. Number of public institutions for the mentally retarded, the number of full time employees of these facilities (in thousands), and their annual maintenance budgets (in millions of dollars).

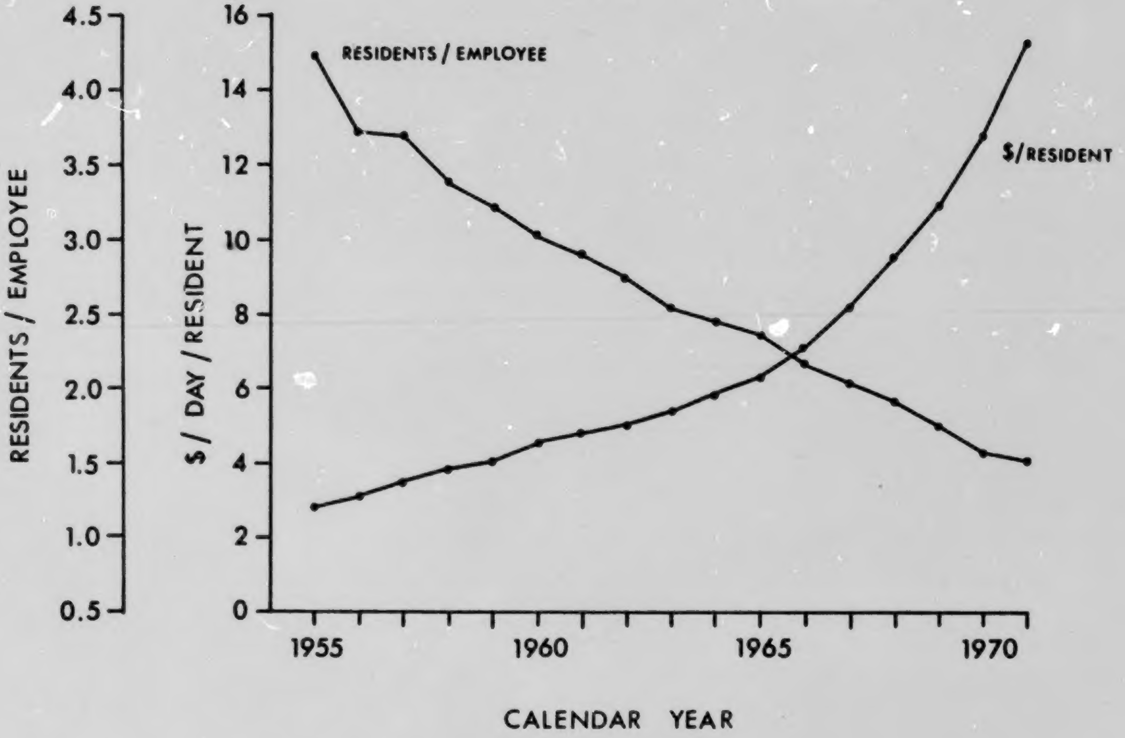

Figure 4. Number of full time employees per resident and daily maintenance cost per resident in public residential facilities for the mentally retarded.

Changes in the number of residents per employee and the number of dollars spent per resident are two of the chief objective indices of whether policy makers are trying to improve residential care. Decreases in the number of residents per employee indicate an effort to provide better care, as do increases in daily maintenance expenditures. By these criteria, our institutions for the retarded are trying harder. There has been a steady decline in the number of residents per employee since 1955. In that year, there were 4.23 residents for each full-time employee in our public institutions. In 1971, there were only 1.52 residents per employee. Daily costs per resident have increased steadily since 1955, from $2.84 to $15.18 in 1971. More important, perhaps, the rate of this acceleration began to increase in 1965. Prior to 1965, the annual increase in daily costs was almost constant. From 1965 on, the increase became progressively larger each year. This acceleration suggests that the decrease in institutional census which began in 1967 is the result of policy changes that occurred in 1965 or earlier.

Figures 5 and 6 provide a more analytic view of admission and release practices. Figure 5 breaks admissions into the number of people entering public residential facilities for the first time and the number re-entering following previous admission and release. It compares first admission and readmission trends with the number of residents released in each year between 1961 and 1971. As we saw in Figure 2, releases began their ever upward trend in 1965. What we could not see in the total admission data shown in Figure 2 is that first admissions began a continuing fall in 1965. In contrast, readmissions rise after 1965, and the rise is steeper the closer we come to 1971. In other words, the year in which expenditures began to increase more rapidly is also the year that first admissions began to fall and releases began to rise. It looks as if the nation decided to make it possible for more mentally retarded people to live outside of residential facilities by increasing care and treatment in those facilitites. If this is so, why did readmissions increase?

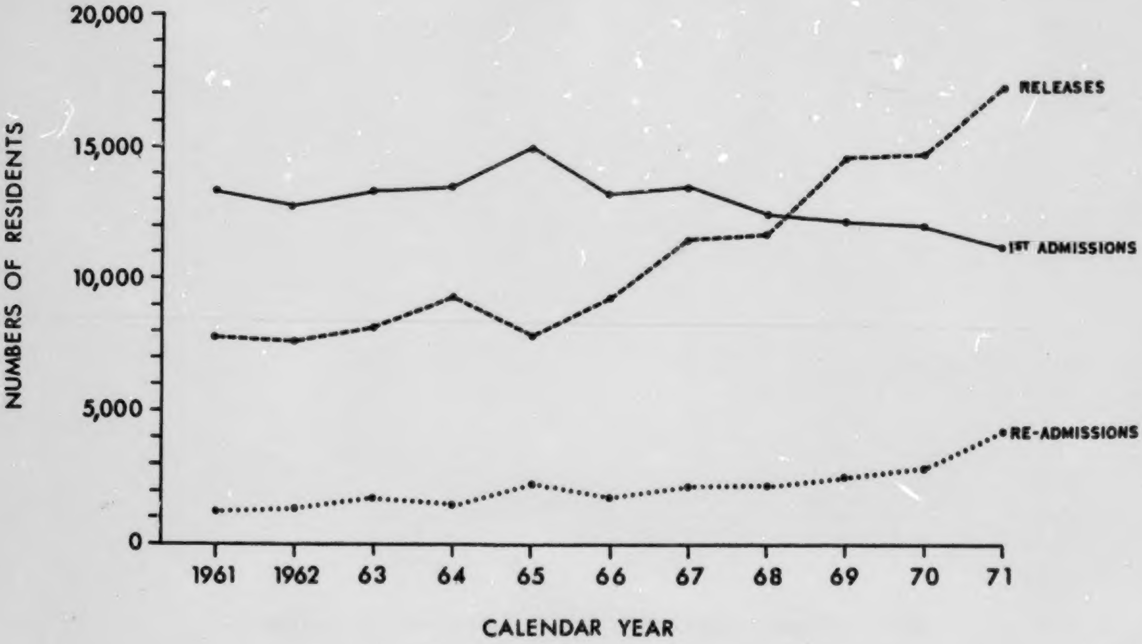

Figure 5. Number of releases from and first and readmissions to public residential facilities for the mentally retarded from 1961 to 1971.

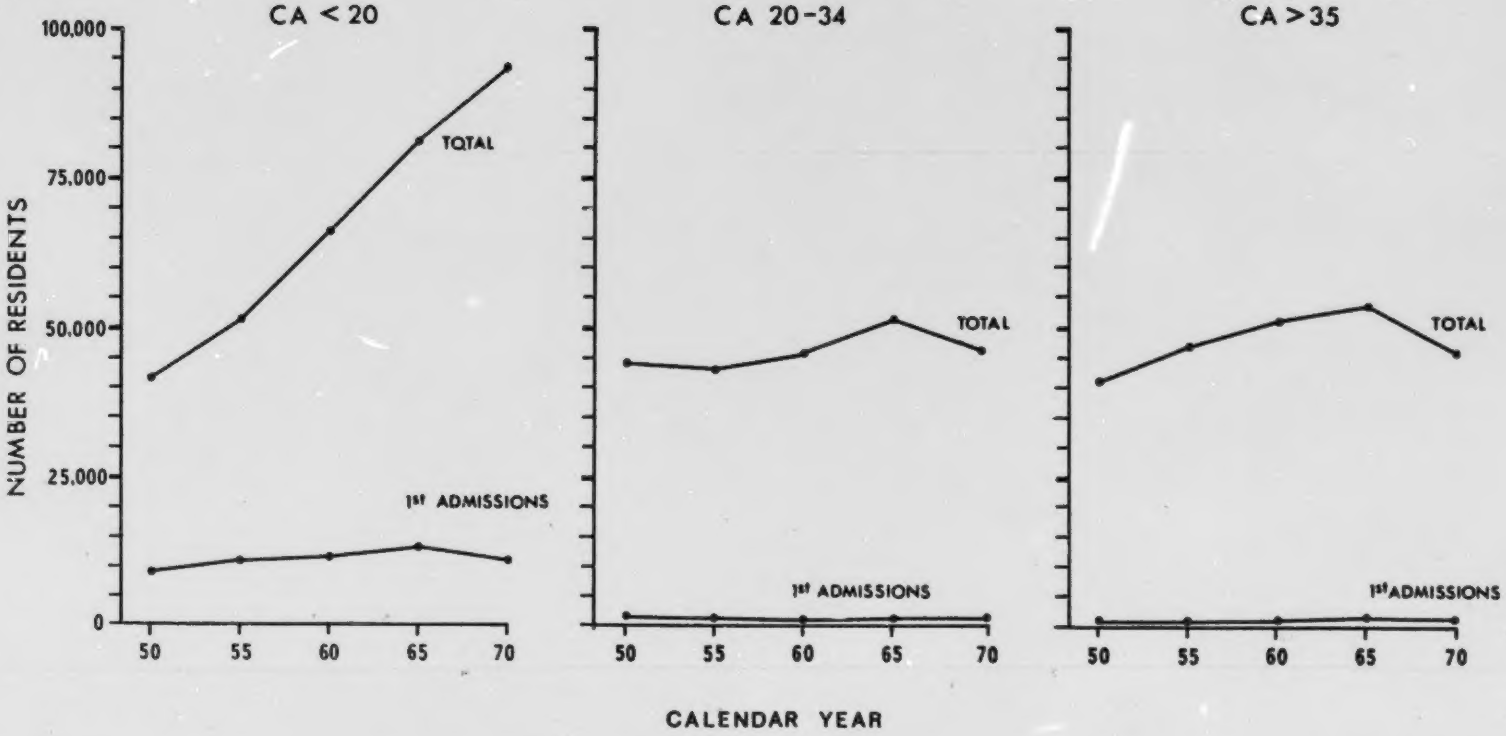

Figure 6. Total number of residents in and first admissions to public facilities for the mentally retarded in each of three chronological age (CA) ranges.

Institutions released very few mentally retarded people prior to 1965, and most of those who were released stayed released. Few were readmitted. Together, these two facts show that institutional personnel were conservative in their judgments about who could survive outside of a residential facility. The policy change which seems to have occurred about 1965 called for the release of more residents. Despite the liberalization of release policy, conservative practices probably continued until they had to be changed. When the freer policy came along, residents most like those who would have been released under the conservative policy were released first. Eventually, all such residents were gone, and less conservative judgments had to be made about who could maintain themselves outside of the institution. Some time after institutions began freeing residents whom they formerly judged unready for placement, more of those released began to fail in their community placements. Residential facilities have less control over whom they admit than over whom they release. Consequently, the readmission rate increased, but only several years after the rate of release increased. By this rationale, the readmission rate should be even higher now than it was in 1971. The data to test this prediction have been collected, but they have yet to be released to the public. However, the data that are available do allow us to test other expectations.

Which retarded residents would a conservative decision maker release first? He would release those who are most capable. On the average, that would mean releasing the least retarded and those who had reached their ultimate developmental level. It would also mean releasing those who could be legally and economically responsible for themselves; in other words, those who were past their school years. Figure 6 speaks to this expectation. Its three upper curves show the number of residents in facilities for the mentally retarded from each of three age groups. It reveals a sharp increase in residents under 20 years of age from 1950 to 1970. The decrease in total institutional census which began in 1967 does not apply to residents under 20. It only applies to those over 20. There were decreases from 1965 to 1970 in the number institutionalized who were between 20 and 34 and who were over 35. This pattern is precisely consistent with the foregoing analysis. Moreover, if the new policy continues, we should eventually see a decrease in the number of younger residents in our public facilities for the mentally retarded. This follows from the fact that so few older mentally retarded people are being newly admitted to our nation's residential facilities. The three lower curves in Figure 6 show the number of new admissions in each of three age groups. The overwhelming majority of first admissions are young. In 1970, 87 percent of the first admissions to our nation's residential facilities were below the age of 20.

With the help of Figure 6, we can further characterize the admission and release policies of our nation's residential facilities, both before and after 1965. Admission policies have changed relatively little. As far back as the records go, many more younger than older people have been admitted. In 1955, 79 percent of all first admissions were of persons under 20. That figure has increased very little. What did change about 1965 were our institutions' release practices. Prior to 1965, residents were admitted as children, and they remained institutionalized at least until they were adults. When they reached adulthood, a few of the most capable were released, but most were retained in the institution. This resulted in increasing numbers of institutionalized retarded people of all ages, but particularly those under 20 since most new admissions fell in that range. Institutionalized adults came mostly from the ranks of those admitted as children.

What changed in 1965 was the practice of discharging adults. From 1965 on, increasingly large numbers of adult residents were released. At first, these larger numers were numbers were generally capable people who could have been released in years gone by but were not. Gradually, the more capable residents were discharged, and less able adults were more and more often placed in the community. Recently, this has meant many more readmissions than in previous years, because released adults are less adequate and they are failing more in their community placements.

What precipitated the change in release practices? It would be uplifting to believe that residential release practices were changed by institutional officials in response to the realization that our residential facilities were hellish places to keep people. It is difficult to document that possibility with objective facts. In the 1969 edition of this monograph, I expressed the hope that coming years would see the accumulation of objective data describing our institutions and documenting the quality of their effects upon mentally retarded people. These years have now come and gone, leaving us little evidence of this kind about the conditions and effects of our residential facilities.

Institutionalized Adults in 1967

About the only representative data from the mid-1960s concerning institutionalized people come from a survey conducted by the Social Security Administration. The survey concerned itself with institutionalized people over 18 years of age. The median number of residents in facilities housing such retarded people was 1,820. The median length of adults' stay in institutions was 16.3 years. More than a third of the institutionalized retarded adults had lived in their residential facilities for over 20 years. The most common reasons for having institutionalized these people were that they needed to be watched or looked after more carefully than was possible in their homes and that they were judged to need permanent care. Sixty-seven percent of these adults did not go on leave from their institution during 1967. Only 3 percent went on leave as often as once a month.

In the judgment of their institutional caretakers, over 5 percent of these adults could have been prepared for release within 6 months, but these same care-givers expected that only 1 percent would be released. Institution personnel expected 99 percent of the retarded adults to remain institutionalized for the rest of their lives: 95 percent because they seemed incapable of non-institutional life, and 4 percent because no one would get around to letting them go.

The National Center for Health Statistics conducted a survey in 1967 of licensing and regulatory agencies for residential facilities serving mentally retarded persons. Nine states had none. In all 50 states, only one facility had a formal hearing during 1967 to show cause why its license should not be revoked. No facility, private or public, was prosecuted in court that year.

Even though the data are spare, their message is grim. In 1967, most residents had been institutionalized as children because their families felt unable to meet their needs or were overwhelmed by the possibility of having to do so indefinitely. Once institutionalized, most were abandoned by their families. Most institutions acted like huge storehouses. They freed very few of their thousands. Institutional employees understood that even among those residents they knew could be prepared for release, most would not be. And no one monitored most of these facilities.

It is not clear that this message contributed in any way to the change in institutional release practice. The fact remains that most states in our nation *have* changed their approach to institutional programming for the mentally retarded. Of course, some changed before others, and some have yet to change. Some that have changed still have a long way to go. Indeed, some observers say that all residential facilities have far to go. The statistics I have reported, they say, don't tell enough of the story. Many of our nation's residential facilities remain foul and offensive places. Their buildings are still not repaired; neither they, the residents, nor their food are clean; many residents still atrophy or die for lack of basic physical care.

Differences Between States

It is true that the basic facts I have reported cannot convey the horror of everyday life in most of our residential facilities. But these facts cannot be argued away either, as observers, undocumented accounts of horrible scenes can be. So, let us see who has come the furthest by out objective measures, and who these measures say has yet to take up the challenge to change.

Four objective indices can be used to make state-by-state evaluations of institutional policy for mentally retarded persons. They are: (1) the number of new admissions per 100,000 people in the state; (2) the number of institutionalized residents per 100,000 population; (3) the daily maintenance cost per resident; and, (4) the number of full-time staff per 100 mentally retarded patients under care. I will not consider (4), number of staff per patient, because for present purposes it adds no information over (3), daily costs. Table 2 shows the three measures for each year from 1960 to 1971. It presents the facts separately for 49 of our states and the District of Columbia. (Nevada has no residential facility for retarded persons.) The average values for the whole nation are also given in Table 2.

TABLE 2

(1) Daily Maintenance Expenditures Per Patient Under Treatment
(2) Number of Resident Patients Per 100,000 Population and (3) Number of First Admissions Per 100,000 Population to United States Public Institutions for the Mentally Retarded, 1960-1971.

			1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
United States	1.	$/Day	4.20	4.43	4.81	5.14	5.63	6.09	6.71	7.60	8.87	10.08	11.64	13.65
	2.	Residents/100,000	91.90	92.60	94.80	94.80	95.20	97.60	98.80	98.60	97.70	94.20	94.20	88.80
	3.	Admissions/100,000	7.60	7.30	6.90	7.20	7.10	7.80	6.80	6.60	6.30	6.20	5.90	5.40
Alabama	1.	$/Day	2.53	2.52	2.87	3.03	3.06	3.15	3.74	3.88	4.71	5.79	6.37	6.86
	2.	Residents/100,000	52.00	56.50	59.30	60.60	62.60	63.40	64.50	65.60	67.40	66.70	67.50	64.10
	3.	Admissions/100,000	2.10	8.10	5.30	4.50	5.90	4.70	4.00	4.30	1.20	1.30	1.70	2.80
Alaska	1.	$/Day	-	-	-	-	-	-	-	-	-	-	35.62	38.78
	2.	Residents/100,000	-	-	-	-	-	-	-	31.20	40.10	40.60	40.50	36.00
	3.	Admissions/100,000	-	-	-	-	-	-	-	14.30	N.R.	6.30	5.30	6.70
Arizona	1.	$/Day	2.73	2.87	3.03	3.17	3.44	4.16	4.89	6.00	6.03	6.09	7.32	8.71
	2.	Residents/100,000	44.70	45.30	50.80	54.70	56.60	55.90	55.60	55.60	60.40	58.80	55.70	52.00
	3.	Admissions/100,000	5.60	7.90	11.10	10.30	7.70	3.90	4.30	2.60	5.20	2.30	1.60	1.70
Arkansas	1.	$/Day	3.99	4.54	5.48	4.64	5.50	5.78	4.86	6.37	7.64	8.17	8.86	13.50
	2.	Residents/100,000	12.50	14.90	14.30	23.70	24.10	28.00	33.80	34.10	43.30	56.90	67.60	65.00
	3.	Admissions/100,000	13.90	4.50	1.10	9.90	2.30	5.50	10.90	2.80	11.70	19.20	16.80	4.30
California	1.	$/Day	6.33	6.69	7.04	8.13	8.73	9.39	10.23	11.31	12.30	13.23	16.38	19.56
	2.	Residents/100,000	72.90	72.50	70.10	73.70	72.30	71.90	71.10	71.40	71.10	65.80	58.70	52.60
	3.	Admissions/100,000	9.80	6.00	4.60	8.20	4.60	6.10	5.60	5.90	5.70	3.50	2.80	3.10
Colorado	1.	$/Day	4.47	4.73	5.56	6.44	6.97	7.85	7.66	9.68	9.30	12.21	15.73	16.73
	2.	Residents/100,000	91.40	86.70	89.00	87.40	93.80	94.20	100.10	121.00	122.90	111.30	98.20	91.70
	3.	Admissions/100,000	7.00	7.10	5.10	5.20	13.10	6.40	6.40	12.50	8.90	7.90	3.80	4.70
Connecticut	1.	$/Day	5.20	5.58	5.97	6.12	6.50	6.99	8.17	8.58	9.65	11.34	12.69	14.38
	2.	Residents/100,000	140.50	138.20	135.90	133.70	132.70	129.00	137.00	141.70	139.90	137.20	134.90	129.70
	3.	Admissions/100,000	8.80	10.20	11.70	8.40	6.90	5.50	11.20	12.00	11.10	9.40	9.30	10.30
Delaware	1.	$/Day	4.71	4.83	4.79	4.67	5.41	5.99	6.69	7.67	8.63	10.55	11.78	12.17
	2.	Residents/100,000	128.80	127.40	126.90	122.20	117.10	115.90	114.50	120.60	112.00	106.40	105.00	103.10
	3.	Admissions/100,000	10.40	6.90	8.90	6.60	12.60	9.70	7.10	3.70	3.20	4.30	5.80	4.10

TABLE 2 (cont.)

			1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
Dist. of Col.	1.	$/Day	7.08	7.52	4.94	5.38	7.89	7.83	5.98	5.21	6.90	11.19	11.82	13.02
	2.	Residents/100,000	128.10	135.80	141.50	147.00	154.30	150.00	162.80	162.10	166.40	163.90	169.20	162.00
	3.	Admissions/100,000	9.40	12.50	12.40	11.60	7.00	10.30	8.10	9.40	9.50	5.90	5.90	6.00
Florida	1.	$/Day	5.03	5.15	6.05	6.28	6.81	6.86	7.01	7.53	10.91	10.92	10.75	11.87
	2.	Residents/100,000	29.40	32.70	61.10	64.80	67.10	70.30	76.10	85.30	91.80	91.40	91.60	89.00
	3.	Admissions/100,000	7.10	10.00	8.70	9.70	7.40	7.50	11.30	8.80	10.40	14.80	6.70	6.20
Georgia	1.	$/Day	3.61	3.95	3.82	4.56	5.32	6.66	6.94	8.42	10.13	11.45	15.92	20.85
	2.	Residents/100,000	35.30	37.30	39.50	40.50	37.80	38.90	43.70	40.90	41.10	37.50	41.60	44.30
	3.	Admissions/100,000	5.10	4.80	4.30	3.40	3.80	3.70	2.80	3.30	3.40	3.60	6.50	8.40
Hawaii	1.	$/Day	-	5.23	6.05	6.75	6.32	6.68	7.82	8.67	9.11	9.22	11.84	14.38
	2.	Residents/100,000	-	137.70	133.30	133.80	131.90	127.20	121.70	115.50	109.30	100.80	104.80	102.80
	3.	Admissions/100,000	-	6.00	6.30	10.40	9.90	10.60	8.80	7.10	5.70	7.50	10.50	5.80
Idaho	1.	$/Day	3.69	4.56	4.87	5.28	5.87	5.06	6.09	5.51	6.53	8.11	6.53	12.34
	2.	Residents/100,000	112.90	108.80	106.20	105.70	99.90	105.80	105.40	100.00	99.30	98.20	92.40	80.10
	3.	Admissions/100,000	1.50	2.80	3.90	3.10	1.30	14.30	10.70	9.20	15.20	15.80	8.30	8.70
Illinois	1.	$/Day	3.03	3.12	3.56	3.76	4.66	5.59	7.08	8.70	11.01	11.58	13.53	15.97
	2.	Residents/100,000	100.20	98.90	99.20	96.80	94.50	94.30	92.00	88.00	83.80	77.70	71.30	59.90
	3.	Admissions/100,000	2.80	2.00	3.90	4.60	5.10	5.70	5.10	4.50	1.90	2.90	2.20	2.80
Indiana	1.	$/Day	3.86	4.05	4.66	4.87	5.16	6.17	7.16	8.01	10.46	11.51	12.09	13.30
	2.	Residents/100,000	77.90	77.20	81.70	79.10	78.30	78.80	80.40	79.30	75.90	73.80	69.50	67.20
	3.	Admissions/100,000	5.60	5.00	7.30	3.40	4.00	5.80	5.90	4.50	1.30	3.10	2.20	2.40
Iowa	1.	$/Day	3.46	3.76	4.15	4.85	5.38	5.95	7.66	8.25	11.59	13.38	14.35	15.65
	2.	Residents/100,000	117.60	107.20	92.50	82.40	77.50	72.90	67.80	67.00	60.70	55.60	57.50	54.30
	3.	Admissions/100,000	4.80	6.30	5.40	7.60	6.80	5.30	3.50	5.30	3.90	3.80	3.00	2.80
Kansas	1.	$/Day	6.37	7.58	8.86	9.90	10.37	10.63	11.09	11.54	12.72	13.75	15.26	16.59
	2.	Residents/100,000	93.90	89.30	87.80	86.50	89.80	87.10	88.10	85.90	87.10	83.70	91.40	90.60
	3.	Admissions/100,000	13.40	10.40	8.80	7.60	7.20	7.50	9.20	6.70	5.50	6.80	9.60	8.80
Kentucky	1.	$/Day	-	-	2.47	4.30	6.13	6.47	7.51	9.17	8.76	8.98	9.74	10.72
	2.	Residents/100,000	38.00	40.30	38.40	34.20	33.40	35.30	34.60	33.90	34.40	32.90	31.20	30.40
	3.	Admissions/100,000	3.90	3.20	2.70	1.00	2.90	7.20	3.40	2.90	3.80	2.90	3.90	4.10

TABLE 2 (cont.)

		1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
Louisiana	1. $/Day	3.53	4.55	4.82	5.05	5.11	6.27	7.53	8.91	9.82	10.99	10.86	13.04
	2. Residents/100,000	47.70	48.50	49.80	53.70	52.40	59.70	63.60	65.60	75.70	75.30	82.10	82.70
	3. Admissions/100,000	3.60	3.90	4.20	6.70	2.60	8.70	7.70	6.80	12.10	6.80	9.50	5.60
Maine	1. $/Day	4.21	4.88	5.83	6.66	6.18	7.06	8.28	8.36	9.36	10.00	13.97	14.64
	2. Residents/100,000	138.10	127.70	118.60	113.90	111.90	110.30	102.00	100.40	94.30	86.90	81.40	75.30
	3. Admissions/100,000	6.40	7.40	7.50	6.00	23.00	12.80	6.00	4.30	4.40	6.60	8.60	8.80
Maryland	1. $/Day	4.67	4.96	5.23	5.11	6.60	6.13	6.91	7.28	8.45	9.00	11.38	12.69
	2. Residents/100,000	73.90	76.90	79.20	80.40	76.90	80.80	84.30	86.60	84.50	88.10	83.30	82.70
	3. Admissions/100,000	8.40	6.90	7.50	9.20	5.60	8.50	8.50	7.30	8.10	6.80	4.80	5.80
Massachusetts	1. $/Day	4.33	4.86	5.04	5.33	6.06	6.41	6.57	7.80	8.97	9.47	11.96	13.86
	2. Residents/100,000	177.10	176.90	170.90	166.50	164.90	163.90	160.90	154.60	147.30	143.00	133.60	126.90
	3. Admissions/100,000	11.10	9.70	10.70	7.40	5.70	7.10	5.70	5.60	5.60	6.30	4.90	4.70
Michigan	1. $/Day	5.60	5.88	5.98	6.03	6.44	6.79	7.56	8.38	9.73	11.62	12.67	16.06
	2. Residents/100,000	146.10	148.80	151.60	152.10	150.90	152.20	150.30	147.00	149.50	140.40	133.60	122.10
	3. Admissions/100,000	10.80	9.30	7.40	10.60	8.90	12.80	8.70	11.80	7.60	7.50	3.80	3.80
Minnesota	1. $/Day	4.09	4.11	4.42	4.77	4.48	5.34	5.86	5.99	8.11	9.62	12.01	15.00
	2. Residents/100,000	155.90	162.00	166.60	162.60	159.60	159.20	153.40	157.20	142.60	131.00	113.70	103.50
	3. Admissions/100,000	11.00	14.90	12.50	8.50	5.90	10.30	5.50	6.10	5.90	5.80	4.40	4.80
Mississippi	1. $/Day	1.63	1.55	1.75	1.62	2.05	2.45	2.82	2.95	3.28	3.79	4.61	5.21
	2. Residents/100,000	52.40	52.50	52.00	47.20	51.60	52.00	56.20	54.30	58.30	57.10	61.30	62.70
	3. Admissions/100,000	1.80	2.50	2.40	6.50	5.50	7.70	4.00	4.90	5.80	4.60	3.70	5.70
Missouri	1. $/Day	3.23	4.11	4.18	4.70	5.58	5.32	6.06	7.09	7.10	9.13	9.75	9.97
	2. Residents/100,000	58.10	57.30	57.00	56.00	55.60	55.10	57.00	56.60	57.50	55.10	54.70	48.20
	3. Admissions/100,000	4.20	5.00	3.80	4.40	3.20	4.50	4.90	4.60	18.50	18.40	22.20	19.00
Montana	1. $/Day	2.90	2.64	2.78	2.91	3.38	3.65	4.39	5.04	7.69	7.12	8.08	10.85
	2. Residents/100,000	125.70	127.80	122.90	120.40	130.00	132.60	147.30	144.00	125.40	135.50	137.20	122.30
	3. Admissions/100,000	9.40	6.60	0.60	13.30	17.30	8.10	10.90	0.70	1.90	15.80	20.30	6.90
Nebraska	1. $/Day	2.34	2.53	2.57	2.75	2.89	3.09	3.42	3.84	4.38	5.94	7.39	10.64
	2. Residents/100,000	155.40	155.10	154.90	155.70	161.00	162.60	164.50	163.50	147.50	140.60	119.40	95.50
	3. Admissions/100,000	7.60	8.60	7.80	7.40	10.50	7.80	7.60	6.80	6.20	4.60	10.70	2.50

TABLE 2 (cont.)

			1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
New Hampshire	1.	$/Day	4.49	4.42	4.84	4.94	4.89	6.05	5.41	5.97	6.61	6.91	7.75	9.46
	2.	Residents/100,000	133.60	140.80	140.80	138.40	137.30	151.10	167.60	146.00	150.40	140.80	132.20	122.40
	3.	Admissions/100,000	10.30	11.60	6.60	4.10	6.60	9.10	9.00	6.70	9.40	4.50	10.20	4.00
New Jersey	1.	$/Day	4.09	4.33	4.61	4.57	5.03	5.55	6.57	7.32	8.66	9.39	10.75	12.51
	2.	Residents/100,000	94.20	91.10	89.50	87.70	86.10	89.00	94.90	95.90	95.60	94.10	96.40	99.40
	3.	Admissions/100,000	3.70	3.30	4.60	4.20	4.40	7.30	10.70	6.90	3.80	3.10	6.20	6.70
New Mexico	1.	$/Day	4.84	5.12	5.91	5.70	5.72	6.84	9.80	11.16	10.82	12.77	12.35	13.36
	2.	Residents/100,000	23.90	24.10	23.80	32.40	48.20	55.60	60.70	70.10	77.10	78.10	70.90	67.40
	3.	Admissions/100,000	6.00	2.30	1.90	10.80	25.10	10.40	9.20	14.40	9.40	6.50	3.90	4.80
New York	1.	$/Day	4.27	4.27	4.84	5.10	6.05	6.28	6.50	7.50	8.31	10.15	12.08	14.90
	2.	Residents/100,000	140.00	132.70	137.50	138.00	132.80	151.50	150.20	155.60	152.30	147.00	146.30	141.10
	3.	Admissions/100,000	11.50	9.80	9.80	9.70	9.00	8.60	6.90	7.00	5.80	5.60	5.50	3.90
North Carolina	1.	$/Day	4.09	4.31	4.17	4.60	5.16	5.89	6.48	7.24	8.34	8.75	10.91	11.29
	2.	Residents/100,000	70.00	80.10	78.90	86.80	89.60	90.90	89.70	90.80	93.30	94.60	102.30	96.10
	3.	Admissions/100,000	11.10	11.90	11.20	13.50	9.00	10.30	8.30	8.60	8.20	10.20	9.30	9.20
North Dakota	1.	$/Day	3.03	3.33	3.80	3.99	4.22	4.42	4.59	5.07	6.53	5.91	6.62	5.50
	2.	Residents/100,000	193.20	193.70	192.20	186.30	188.80	190.00	189.00	220.50	252.00	249.30	246.60	215.20
	3.	Admissions/100,000	13.50	15.60	7.40	7.90	8.00	7.80	6.70	11.80	10.90	7.90	7.90	8.80
Ohio	1.	$/Day	3.97	4.12	4.53	4.69	4.50	4.62	4.78	5.34	6.72	7.21	8.12	9.04
	2.	Residents/100,000	79.70	76.60	96.50	96.80	98.70	97.70	97.10	93.20	90.70	87.70	89.00	84.60
	3.	Admissions/100,000	7.00	5.90	5.10	4.30	7.40	6.10	6.20	5.40	5.80	4.90	4.40	3.70
Oklahoma	1.	$/Day	1.86	1.84	1.84	2.79	3.95	5.28	7.07	9.11	10.13	10.22	11.42	13.73
	2.	Residents/100,000	90.60	87.20	90.10	89.80	96.10	96.00	84.30	79.00	92.50	78.30	76.70	74.60
	3.	Admissions/100,000	6.20	5.50	6.20	5.50	13.40	27.70	9.90	9.40	9.20	10.00	9.70	6.90
Oregon	1.	$/Day	3.33	4.13	4.54	4.60	5.00	5.26	6.76	7.30	8.81	9.10	11.53	12.37
	2.	Residents/100,000	130.60	140.30	140.70	140.40	129.40	116.40	147.90	169.10	152.00	145.10	135.90	129.10
	3.	Admissions/100,000	37.70	17.60	11.00	10.30	6.10	8.30	9.30	13.40	7.80	8.90	4.10	3.70
Pennsylvania	1.	$/Day	4.25	4.31	5.03	5.35	5.76	6.24	6.99	7.98	9.29	11.19	15.38	17.08
	2.	Residents/100,000	87.70	90.60	90.90	91.50	92.40	98.30	100.50	101.50	98.80	92.00	90.20	87.00
	3.	Admissions/100,000	3.40	6.20	7.90	4.10	3.70	7.70	5.30	4.30	2.40	2.40	3.70	3.00

TABLE 2 (cont.)

			1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
Rhode Island	1.	$/Day	4.67	5.26	5.23	6.01	6.18	8.85	10.16	11.43	13.24	13.84	15.01	17.14
	2.	Residents/100,000	106.80	111.00	111.30	112.20	115.60	110.30	105.60	100.90	97.30	98.60	92.20	92.60
	3.	Admissions/100,000	6.30	8.50	9.50	9.90	5.00	2.20	3.90	5.60	5.00	3.80	3.30	3.10
South Carolina	1.	$/Day	2.35	2.58	2.71	2.95	3.08	3.36	3.73	4.20	2.28	5.96	6.80	7.41
	2.	Residents/100,000	112.30	112.10	110.90	108.30	114.80	114.00	118.20	114.30	127.90	133.50	144.40	142.00
	3.	Admissions/100,000	15.60	5.90	5.10	6.00	11.70	6.70	9.90	10.90	23.00	24.60	20.80	14.70
South Dakota	1.	$/Day	2.16	2.13	2.34	2.25	3.04	3.39	2.96	3.11	5.99	6.17	6.28	7.01
	2.	Residents/100,000	154.80	153.90	155.20	159.10	167.00	188.20	193.30	190.80	187.30	185.30	181.10	175.20
	3.	Admissions/100,000	10.80	8.70	7.50	12.30	18.90	7.20	9.20	13.00	9.40	9.80	8.90	10.80
Tennessee	1.	$/Day	2.47	3.04	3.28	3.72	4.42	5.04	5.68	6.74	7.83	9.56	10.92	12.34
	2.	Residents/100,000	39.40	44.10	45.30	47.60	51.80	53.10	53.90	55.80	57.80	63.00	71.60	71.80
	3.	Admissions/100,000	5.00	6.80	4.20	5.10	6.70	5.40	2.70	4.50	4.90	5.60	11.20	5.90
Texas	1.	$/Day	3.00	3.10	3.44	3.78	3.70	3.91	4.65	5.09	6.64	7.55	8.67	9.29
	2.	Residents/100,000	72.80	77.30	81.70	81.80	94.40	97.30	96.10	96.10	96.10	96.10	100.30	104.90
	3.	Admissions/100,000	4.90	10.10	11.20	12.10	13.90	12.00	6.80	8.60	6.40	5.50	8.40	9.30
Utah	1.	$/Day	2.85	3.24	3.31	4.04	4.43	4.76	4.74	5.22	5.90	6.98	10.48	13.02
	2.	Residents/100,000	104.40	100.00	94.10	90.70	91.20	85.50	109.40	80.10	77.40	110.50	81.80	82.20
	3.	Admissions/100,000	8.40	7.30	7.20	5.30	5.50	2.60	1.80	2.90	8.90	4.80	7.80	8.60
Vermont	1.	$/Day	3.61	3.52	3.77	3.88	4.36	4.47	5.34	7.00	7.37	7.69	9.79	12.71
	2.	Residents/100,000	151.70	156.20	158.40	155.30	164.40	164.10	163.70	155.10	155.50	150.40	141.40	126.90
	3.	Admissions/100,000	8.20	10.30	9.90	11.90	17.30	11.90	11.80	7.60	11.20	16.70	12.40	13.90
Virginia	1.	$/Day	3.43	3.48	3.87	3.88	4.02	4.21	4.38	5.23	5.79	6.35	7.20	8.32
	2.	Residents/100,000	72.90	73.70	73.80	74.30	75.80	80.90	80.20	80.10	80.90	80.60	82.00	81.10
	3.	Admissions/100,000	6.50	6.40	7.60	6.40	7.60	9.40	7.70	7.00	6.90	5.60	6.50	5.80
Washington	1.	$/Day	5.55	5.90	6.16	6.10	6.31	7.10	7.05	8.49	10.39	12.74	14.89	15.75
	2.	Residents/100,000	128.30	134.70	132.60	129.70	132.00	134.80	140.10	127.70	111.30	121.50	112.10	100.20
	3.	Admissions/100,000	7.20	12.80	4.40	5.80	8.20	7.70	12.00	6.80	7.50	5.90	3.90	5.00
West Virginia	1.	$/Day	3.93	4.09	4.64	4.92	4.97	6.51	8.06	8.60	10.06	10.57	11.49	13.23
	2.	Residents/100,000	19.20	19.00	18.70	18.50	23.60	28.50	26.10	26.60	26.00	25.90	26.40	26.50
	3.	Admissions/100,000	3.40	2.10	1.10	1.70	6.70	6.30	5.00	2.20	2.10	2.20	1.10	1.40

TABLE 2 (cont.)

			1960	1961	1962	1963	1964	1965	1966	1967	1968	1969	1970	1971
Wisconsin	1.	$/Day	5.73	6.08	6.77	7.18	7.69	8.76	9.91	11.63	14.31	16.51	14.11	20.88
	2.	Residents/100,000	90.30	91.30	91.80	91.50	90.60	90.50	90.60	88.20	86.50	89.50	85.60	83.00
	3.	Admissions/100,000	10.10	6.40	5.80	6.50	6.20	6.10	7.40	5.80	7.10	7.40	6.50	7.40
Wyoming	1.	$/Day	4.14	4.43	4.92	5.57	5.70	6.26	5.31	7.09	6.99	6.80	8.00	7.81
	2.	Residents/100,000	185.70	175.40	170.70	168.90	167.90	169.20	220.00	211.70	203.40	219.90	212.50	210.40
	3.	Admissions/100,000	6.10	16.80	10.40	9.10	11.40	9.20	12.00	8.90	7.20	9.60	6.60	7.40

The data allow clear conclusions about most states' policies toward institutionalizing mentally retarded people. Consider the first state listed, Alabama. Its daily maintenance costs were consistently among the very lowest in the nation. Not until 1968 did it spend as much as the average state spent in 1960. Alabama not only started out spending far less than other states, it increased its rate of expenditures more slowly. Table 2 shows that between 1970 and 1971, the average increase in daily maintenance costs was $2.01. Alabama increased $0.49, which is less than 25 percent of the average gain. Only Delaware, Missouri, North Dakota, and Wyoming increased their expenditures less than Alabama from 1970 to 1971. In 1971, Alabama spent less than half the national average to maintain its retarded residents. Only Mississippi and North Dakota spent less per patient under care.

While it has spent so little to care for its retarded residents, Alabama has mercifully institutionalized relatively fewer people than most other states. During 1971, the United States as a whole placed about 89 of every 100,000 people in residential facilities for the mentally retarded. The number per 100,000 Alabamans was only 64; only nine states had lower rates in 1971. While the per capita rate of institutionalization for mental retardation was consistently low in Alabama, it increased every year from 1960 to 1970. The average state began in 1967 to house proportionately fewer of its citizens in its residential facilities for the mentally retarded. Not Alabama. Its institutional census did not begin to decrease until 1971, despite the fact that its rate of first admissions decreased consistently from 1961 to about 1970. From 1968 to 1971 its first admission rate was the lowest in the nation though it was followed closely by West Virginia.

The facts paint an unflattering picture of Alabama's treatment of its institutionalized mentally retarded population. Its rate of expenditure was niggardly. The quality of its care must have been abysmally low. Its per capita number of residents increased while its per capita first admissions decreased to practically zero. It was clearly not discharging residents as rapidly as other states, despite the fact that its institution was severely overfilled. Had it not been overfilled, its rate of first admission and per capita cost would have been higher. The data say that Alabama provided less adequate residential care for mentally retarded people than any other state in the nation. This conclusion finds support in the subsequent verdict of the court in a case against Partlow, Alabama's residential facility. The coincidence of our data's verdict and that of the court says that, limited as they are, these data tell humanly valid stories. Let us turn to another state whose residential policies have been questioned in court, New York.

Unlike Alabama, New York spent slightly more than the average state for the maintenance of its mentally retarded residents. New York has not been a national leader, but it has a respectable relative standing. It had a substantially higher per capita rate of institutionalization than Alabama. In 1971, 141 out of every 100,000 New Yorkers resided in residential facilities for the mentally retarded. This is more than twice Alabama's rate of 64 per 100,000. Only North Dakota, South Dakota, South Carolina, and Wyoming had higher per capita institutionalization rates. All four of these states were near the bottom in daily maintenance expenditures for their residents.

Should we conclude that because New York spent more it provided better care? Its rate of first admissions suggest not. Like Alabama, New York admitted fewer and fewer residents every year from 1960 to 1971. Moreover, its per capita rate of institutionalization grew through most of those years. The combination of a growing residential population and decreasing first admissions signals overcrowding and inadequate care. In the early 1970s, the courts responded to the conditions so signalled by ordering relief measures on behalf of the residents of New York's Willowbrook facility. Again, our objective measures anticipated necessary remedial measures. Now, consider a state whose residential policies for mentally retarded persons have been hailed as outstanding, Connecticut.

Connecticut consistently spent more than the average state for the maintenance of its mentally retarded residents. Its increase in maintenance rates kept pace with the nation's average increase. It began the 1960s spending more and it increased its expenditures as rapidly as the nation as a whole. Unlike Alabama and New York, it maintained a high rate of first admissions. Moreover, it has decreased its per capita residency rate every year since 1967. The conclusion is that throughout the early 1960s, Connecticut released retarded people as fast as it admitted them to its residential facilities. Unlike the nation as a whole, Connecticut continued in the late 1960s to use institutional placement as extensively as before.

Also unlike the nation as a whole, Connecticut released its institutionalized at a high rate. In other words, it provided relatively short-term residential placement for a fairly high proportion of its population, and it spent relatively large amounts of money to care for those residents while they were institutionalized.

Connecticut and Alabama seem extremes in how the states provide residential services for the mentally retarded. Between these two, how do the other states rank themselves? Which are trying the hardest to provide quality institutional care and to promote extra-institutional living for the mentally retarded? To answer these questions I built a simple formula to quantify and combine data like that reported in Table 2.

The formula considers four factors. It weights changes in release and admission policies most heavily. Those states which have clearly begun to reduce their per capita rate of institutionalization are given most credit. Those who have not reduced their census but have nevertheless clearly decreased their rate of new admissions are given the least credit.

The second factor which the formula considers is the state's history of maintenance expenditures. If the state has been consistently above the national average, it is given extra credit. If it has been consistently below the national average, it is penalized.

The third factor is recent change in maintenance costs. Those states which have recently increased their maintenance costs substantially more than the national average are given extra credit. The formula penalizes those who have recently decreased their maintenance expenditures or who have increased them only very slightly.

The fourth factor reflects the state's level of capital expenditures as measured by the number of new residential facilities constructed between 1960 and 1970. What is the rationale for each of these factors and how are they entered into the formula?

Release and New Admission Trends. The main thrust of social policy for mentally retarded persons over the past 10 years has been to provide alternatives to institutional placement. That has been the point of legislation to provide educational programs in the public schools. It has been the reason for building small regional centers in urban areas rather than large residential facilities in rural areas. That policy has been based in part on a realization that residential facilities were providing inadequate care, little or no training, and that they were not returning even their most capable residents to the community. One concrete demonstration that a state has acted on this insight is for it to reduce the number of residents in its institutions for the retarded.

My formula gives greatest credit to those states who clearly reduced their institutional population between 1960 and 1971. By clearly reduce, I mean at least two years of decrease and that the decrease proceed at least as rapidly as the increase which preceded it. Table 2 shows that 27 states met this criterion, and they were given 2 points for this factor in my formula. States who failed to show a decrease were given negative scores of either one or two, depending on changes in their rate of new admissions. An increasing or stable rate of institutionalization was judged less negative if it occurred in the presence of an increasing or stable rate of new admissions. Fourteen states showed no decrease in census, with either stable or increasing new admissions, and they were given scores of minus one for this first factor. If new admissions fell while institutionalization rates rose, that was taken as evidence that a state's institutions were filled and that it was providing poor care for its retarded residents. This undesirable pattern of census and admission trends earned nine states scores of minus two for the factor of release and new admission policy. Table 3 shows which states were assigned which scores on this factor. The scores were based on the data reported in Table 2.

Daily Maintenance Level. Some students of the problem of institutional care have concluded that existing residential facilities should be closed because they cannot be improved. Their premise is that residential facilities are captives of their past. If they have been inadequate, inertia will somehow keep them that way. Another way of viewing the contribution of a facility's past is that it dictates how far it must go to attain excellence. Facilities which have a tradition of adequate or good care need not improve as much in order to attain excellence. Those which have a tradition of poor or terrible care must go further to attain excellence. Both of these considerations underlie my formula's second factor.

States are given a positive score of one if they have consistently spent more than the national average daily maintenance for their institutionalized retarded persons. They are given a negative score of minus one if they have

TABLE 3

Ranking of States According to Score in Formula Reflecting Effort to Provide Effective Residential Care, Including Ratings of (1) Release and Admission Trends, (2) Daily Maintenance Level, (3) Changes in Daily Maintenance Expenditures, (4) Increased Capital Expenditures and (5) Sum of These Ratings (Upon Which Ranking is Based).

	Factors				Sum
	(1)	(2)	(3)	(4)	(5)
Illinois	2	1	1	1	5
Connecticut	2	1		1	4
Michigan	2	1	1		4
Pennsylvania	2		1	1	4
California	2	1			3
Colorado	2	1			3
Hawaii	2		1		3
Iowa	2		1		3
Minnesota	2		1		3
Rhode Island	2	1			3
Wisconsin	2		1		3
Delaware	2				2
Idaho	2	-1	1		2
Indiana	2				2
Maine	2				2
Massachusetts	2				2
Nebraska	2	-1	1		2
New Mexico	2				2
Oklahoma	2	-1	1		2
Oregon	2				2
Vermont	2	-1	1		2
Washington	2				2
Kentucky	2	-1			1
Missouri	2	-1	-1	1	1
Montana	2	-1			1
Arizona	2	-1	-1		0
Georgia	-2	1	1		0
Kansas	-1	1			0
New Hampshire	2	-1	-1		0
New York	-2		1	1	0
Alaska	-2	1			-1
Florida	-1		-1	1	-1
Louisiana	-1				-1
Maryland	-1				-1
New Jersey	-1				-1
North Carolina	-1				-1
Utah	-1	-1	1		-1
Virginia	-1				-1
Dist. of Col.	-2			1	-1
Arkansas	-2				-2
Tennessee	-2				-2
Texas	-2				-2
West Virginia	-2				-2
Wyoming	-1		-1		-2
Mississippi	-1	-1	-1		-3
North Dakota	-1	-1	-1		-3
Ohio	-1	-1	-1		-3
South Carolina	-1	-1	-1		-3
South Dakota	-1	-1	-1		-3
Alabama	-2	-1	-1		-4

consistently spent less than the national average. Table 3 shows which 9 states were given credit for consistently above-average maintenance expenditures and which 16 were penalized for below-average expenditures.

Changes in Daily Maintenance Expenditures. A state can work to overcome an inadequate past effort to provide decent care for mentally retarded people, or it can let a strong momentum wane. The third factor in my formula is designed to give credit and lay blame for recent changes from past treatment policies as they are reflected in maintenance expenditures.

States which increased their daily expenditures faster than the national average increased are given a positive score of one. States that have decreased their maintenance costs, or kept them essentially the same, are given a negative score of minus one. Table 3 shows which states were scored negative and which positive.

Increased Capital Expenditures. Daily maintenance costs do not reflect a state's investment in capital items which can improve treatment. I wished in my formula to credit states for investing in modern facilities and improving their old ones. There is no available record of each state's capital expenditures, so I have included an indirect measure, which is the number of new residential facilities constructed between 1960 and 1970. Any state which built four or more new residential facilities between 1960 and 1970 was given a positive score of one.

It seems paradoxical to credit a state both for reducing its per capita rate of institutionalization and for constructing additional residential facilities. But there are reasons to belive that both are positive efforts to serve retarded people better. There is a general consensus that mentally retarded people are served better in small facilities that are located closer to their homes and in metropolitan areas with many extra-institutional social services. Crediting states who have built four or more new facilities assumes that these facilities are not large, self-contained institutions. It is unlikely that any state could afford to construct so many huge self-contained institutions.

Thus, this fourth factor in my formula assumes that any state which has invested in a large number of new residential facilities has embarked upon a program designed to provide short-term residential training close to the resident's home and in cooperation with extra-institutional agencies. Table 3 shows that five states and the District of Columbia built four or more new residential facilities between 1960 and 1970. By way of comparison, 18 states built none during this period; 14 built 1; 2 built 6; and 3 built 4.

How the States Stand. Having assigned values to each of the four factors, my formula calls for the algebraic summation of the scores. The highest possible score is five, since a state could earn two for the first factor and one for each of the others. The lowest possible score is minus four, since a state could earn minus two for the first factor and minus one for factors two and three. Table 3 shows the states' scores on each of the four factors. It ranks the states according to their total scores. Only Illinois made the highest possible score and only Alabama the lowest. Connecticut, Michigan and Pennsylvania fell in the second highest group with scores of four. Mississippi, North Dakota, Ohio, South Carolina and South Dakota make up the next-to-the-bottom group of states. Reference to Table 3 will show where the other states fall. What are we to make of this ranking?

Recognize first that the scores on which this ranking is based do not reflect any absolute standards of treatment. Each state has been compared to the others, not to any criterion of excellence. Thus, even the highest ranking states may not be providing what one would judge to be excellent or even adequate care. Recognize next that the factors upon which this ranking is based are only indirect measures of the quality of treatment. Simply releasing residents, which yields high credit on factor one, does not insure that they are better off than when they were in the institution. Similarly, high maintenance costs do not necessarily mean intensive treatment. People, not their salaries, provide care. What we can tell from this ranking, then, is which states are trying hardest, relative to other states, to provide better institutional care and decent alternatives to residential placement. We can conclude that only four states are making superior efforts. Whether any are succeeding is unclear from this data. Table 3 suggests, however, that if Illinois, Connecticut, Michigan or Pennsylvania are not providing excellent residential care, then none of our states are.

One additional qualifier must be mentioned. These data are not absolutely current. The most recent year for which they are available is 1971. The relative standing of the states may well have changed since then. But as of 1971, Mississippi, North and South Dakota, Ohio, South Carolina and Alabama clearly needed to try harder. They were the states most deserving of class action suits, but only Alabama had been so favored as of 1971. [In later years, suits were filed in Mississippi and Ohio.]

The programs of Illinois, Connecticut, Michigan and Pennsylvania deserve closer scrutiny by those who believe that no residential program serves mentally retarded people well. If it were shown that these states provide inadequate care, then there truly would be reason to seek completely different treatment alternatives for this nation's mentally retarded people.

Finding the Facts is Hard

As in 1969, we still lack objective information about the quality and outcomes of care provided by residential facilities. We have seen that much can be made of the few facts that are available, but much more could be learned from carefully conducted analyses of the various states' service delivery practices and the outcomes of those practices. Moreover, since 1969 an important trend has begun, and it poses even more difficult problems of evaluation than do residential service delivery programs. I refer to the more frequent placement of previously institutionalized retarded people in non-institutional settings. The question must be asked: "Are these released people faring better outside than they were inside the institution?"

The easy response is: "They must be; look how terribly our institutions have been run." But the fact that one kind of program was bad does not make another kind better. Nor does popularity reliably signal quality. The trend to community placement presents an important challenge to our evaluative skills, and I am not optimistic that the challenge will be met.

Consider a depressing fact. It was easier in 1969 than in 1975 to secure the data upon which this analysis was based. In 1969, there was a two-year lag in the reporting of such information. There is now a four-year lag. The yearly publication of provisional data has been stopped, the names of the publications in which the information is reported have unaccountably changed twice, and the people in the relevant Federal agencies usually do not know where to refer you if you wish to find such basic information. The data find their way into Washington, but getting them back out in useable form has become more difficult. This does not bode well for those who would make more sophisticated evaluations of residential or community services for mentally retarded persons. Recall, too, that the first reports of the efficacy of new practices almost always come from their innovators. Subsequent reports are never as positive. We have not yet begun to see clearly and directly how well extra-institutional placement programs are working. May we soon see that they are working well.

Biography

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3. The Origin and Nature of Our Institutional Models

Wolf Wolfensberger

Author's Note

This chapter is an abridged version of one first published in the 1969 edition of the present volume. There have been minor stylistic changes for this edition. More important, two appendices have been omitted—one on maintenance costs for residents in United States public institutions for the mentally retarded, 1848–1966, and one on the origins of certain institutional features.

A full text of this chapter, slightly expanded from the original version, together with the appendices, is available from the Center on Human Policy, 216 Ostrom Avenue, Syracuse, New York 13210.

A number of the names of the various historical figures are still spelled wrongly in this chapter. The problem is that some of their names were spelled incorrectly in their own publications, as seems to have been the case with Nosworthy (1907) which should probably be Norsworthy, or they were spelled inconsistently, as with Murdoch (1903, 1906, 1909) versus Murdock (1917, 1913). In consequence, I have generally used the spelling that is consistent with the reference (source) used, which has the advantage of aiding in bibliographic retrieval.

Since this chapter was first written in 1968, a major new historic text has appeared, *Genetics and American Society*.[1] Anyone with an interest in the development of the "genetic alarm" movement is urged to read it; it provides further evidence of the trends posed in this chapter.

This essay evolved from a series of lectures and an address given before the Wisconsin Association for Retarded Children, Janesville, Wisconsin, May, 1967. The writing of the paper was supported by U.S.P.H.S. Grant HD 00370 from the National Institute of Child Health and Human Development. I am indebted to my colleagues, Frank Menolascino and Sociologist Richard A. Kurtz (now at Notre Dame University) for inspiration and critical reading of earlier drafts.

In the first part of this essay, "The Language of Architecture," I will attempt to define the nature of various models which appear to underlie the design, location and operation of residential facilities for the mentally retarded. In Section II, I will trace the historical evolution of various models that have been and are most prominent in the United States. In both tasks, I will rely heavily on orginal quotations, because I found that statements out of the past often have more direct impact than any attempts to rephrase or summarize them. A final section discusses "The Realities of Institutional Accomplishments."

I. The Language of Architecture

There is probably little disagreement that aside from considerations of cost, or of the nature of the prospective residents, the design of residential facilities for the retarded is affected by attitudes and philosophies held by the designers and by those who guide and direct them. These attitudes and philosophies may be held unconsciously; indeed, the holder may verbally and vehemently deny holding an attitude or philosophy which is strongly expressed in a building.

At least three overlapping dimensions of attitudes and philosophies can be discerned in building design. These are: (1) the role expectancies the building design and atmosphere impose upon prospective residents, (2) the meaning embodied in or conveyed by a building, and (3) the focus of convenience designed into the building; i.e., whether the building was designed primarily with the convenience of the residents, the community, the staff, or the architect in mind.

The term "model" will be encountered frequently in this essay. A human management model is here defined as a consistent pattern in which the behavior of persons is structured by other persons who exercise authority over them. A residential or institutional model consists of the interaction of the physical environment of the residence with the behavioral roles that managers impose upon or elicit from the managed residents.

Perception of the Retarded Person's Role as a Determinant of Institutional Models

A person's social perceptions are profoundly influenced by his basic values and orientation to life. Certain of these values and orientations have clear-cut implications for one's perception or image of the retarded person and his role. And one's image of the retarded person has definite implications for one's conceptualization of the residential service model appropriate for persons cast into the retarded role.

It is a well-established fact that a person's behavior tends to be profoundly affected by the role expectations that are placed upon him. Generally, people will play the roles that they have been assigned. This permits those who define social roles to make self-fulfilling prophecies by predicting that someone cast into a certain role will emit behavior consistent with that role. Unfortunately, role-appropriate behavior will then often be interpreted to be a person's "natural" rather than elicited mode of acting.

In institutions, role performance is influenced not only by the interpersonal stimuli to which an institution resident might be exposed by the institution personnel, but also by the opportunities and demands of the physical environment. For instance, the environment can very clearly express the expectation that a resident is not supposed to assume any responsibility for his actions, or that he is expected to act out violently, etc. By the same token, the physical environment may impose a demand for controlled and highly socialized behavior which is clearly communicated to the prospective resident.

The recent elaboration of the concept of "deviance" by social scientists is of great importance to the understanding of the behavior and management of retarded persons. A person can be defined as deviant if he is perceived as significantly different from others in some overt aspect, and if this difference is negatively valued. An overt and negatively valued characteristic is called a "stigma."

The handicapped person is usually seen as deviant, an expected to play a deviant role. The retarded person, being handicapped and often multiply stigmatized, is deviant by definition. Too often, our texts have tried to explain attitudes toward retarded persons in a narrow sense. However, to understand trends within our field, and society's reponse to retarded persons, one must first understand societal attitudes toward deviancy generally, because a wide range of deviances may elicit similar responses or expectancy patterns from people.

Wilkins suggests that our attitudes toward deviance derive from the Platonic notion that goodness, truth, and beauty are related to each other, and that deviations from norms (truth) are "errors', that, by analogy, must be related to evil and ugliness (Wilkins, 1965).[2] Thus, attitudes toward deviance may be rather generalized. For instance, a person may react emotionally toward retardation much as he does toward blindness, delinquency, and old age.

It is chastening to recall that the retarded in American history were long grouped with other types of deviant groups. In early America, the Puritans looked with suspicion on any deviation from behavioral norms, and irregular conduct was often explained in terms of the supernatural, such as witchcraft. There is reason to believe that retarded individuals were hanged and burned on this suspicion. Later in New England, records show that lunatics, "distracted" persons, people who were *non compos mentis*, and those who had "fits" were all classed together, perhaps with vagabonds and paupers thrown in. Connecticut's first house of correction in 1722 was for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers—and the mentally afflicted. As late as about 1820, the retarded, together with other dependent deviant groups such as aged paupers, the sick poor, or the mentally distracted were publicly "sold" (bid off) to the lowest bidder, i.e., bound over to the person who offered to take responsibility for them for the lowest amount of public support (Deutsch, 1949).[3]

The 10th U.S. census (1880) first combined "defectives," "dependents," and "delinquents" for reporting purposes. The Public Health Service combined "criminals, defectives, and delinguents" as late as the 1920s.

The National Conference on Charities and Correction, between about 1875 and 1920, often grouped the idiotic, imbecilic and feeble-minded with the deaf, dumb, blind, epileptic, insane, delinquent and offenders into one general class of "defectives." Few of us today are aware of the fact that the more contemporary term, "mental defective," was coined to distinguish the retarded from these other "defectives," and it is no coincidence that many state institutions were for both the retarded and the epileptic. During the "indictment period," discussed later, an incredible range of deviances were associated with retardation; indeed, they were seen to be caused by it.

"The chronic insane, the epileptic, the paralytic, the imbecile and idiot of various grades, the moral imbecile, the sexual pervert, the kleptomaniac; many, if not most, of the chronic inebriates; many of the prostitutes, tramps and minor criminals; many habitual paupers, especially the ignorant and irresponsible mothers of illegitimate children, so common in poor houses; many of the shiftless poor, ever on the verge of pauperism and often stepping over into it; some of the blind, some deaf-mutes, some consumptives. All these classes, in varying degree with others not mentioned, are related as being effects of the one cause—which itself is the summing up of many causes—'degeneracy'" (Johnson, 1903).[4]

The first insitutions for retarded persons were built in a period of optimism about mental illness and the education of the deaf and blind, and many facilities for these other deviant groups were erected at that time. The later disillusionment about retardation was also not isolated, but part of a more generalized aversion toward, and virtual persecution of, deviances. Farm colonies were a logical development in mental retardation, but were also part of the history of mental institutions of the same period. During the early part of the century—a very chauvinistic period—numerous writers claimed that a large proportion of retarded persons came from foreign-born stock, contributing to the call for more restrictive immigration laws. This is perhaps an extreme example of how retardation was linked in the minds of many to other types of deviance.

Historically, deviancy has been handled in a number of ways.

- Deviancy can be prevented. A psycho-social means of prevention is not to attach negative value to certain types of differtness. For instance, medieval Catholicism and the more contemporary Hutterites (a religious sect related to the Amish, living a communal life, mostly in the prairie area) did not place excessive value on intellectual achievement, and therefore were less likely to view the retarded as deviant.

- Deviancy can be made undeviant, usually by means such as education, training, and treatment.

- Deviant groups, being perceived as unpleasant, offensive or frightening, can be segregated from the mainstream of society and placed at its periphery. We have numerous examples of this in our society: we segregate Indians in reservations and Blacks in the ghetto; the aged are congregated in special homes, ostensibly for their own good, and these homes are often located at the periphery of our communities or in the country; deaf and blind children who could be taught in the regular schools are sent to residential schools, many of which are on the periphery of, or remote from, population centers; we have (or have had) "dying rooms" in our hospitals to save us the unpleasantness of ultimate deviancy; and the emotionally disturbed and the retarded may be placed in institutions deep in the countryside.

Deviance can be seen to be someone's fault or perhaps a sign that the deviant person's parents had sinned and were being punished by the Lord. The belief that blemish in the offspring is the result of punishment for parental wrongdoing appears to be deeply ingrained in the unconscious of the people. Often, this belief is overtly expressed. It is a belief that had been held by Howe (a leading American pioneer in the field of retardation) and was repeatedly expressed by him. In fact, he even asserted that retardation could result from a person's own wrongdoing (Howe, 1848, 1852, 1866)[5,6,7], e.g.: "It appeared to us certain that the existence of so many idiots in every generation must be the consequence of some violation of the natural laws—that where there was so much suffering, there must have been sin" (1848).[8] Greene (1884) said: "Our wards are innocent of crime or fault. In the large majority of instances, they are the feeble and deformed expressions of parental sins or sorrows."[9] Parental alcoholism, for instance, was widely believed to be a major cause of retardation (e.g., Kerlin, 1886).[10] Perceived to be the result of sin, deviance is something to be ashamed of, hidden, and "put away." The Puritans held views along these lines (Deutsch, 1949).[11]

- Deviance can be destroyed. In the past, some kinds of deviancy were seen to be the work of the devil or other evil forces. As such, the deviant person was evil too and had to be persecuted and destroyed so as to protect society. Destruction of deviant individuals may also be advocated for other reasons such as self-preservation or self-protection. For instance, many societies have condoned the destruction of weaker, less adequate, or handicapped members. This was true of ancient Greece and Rome, of the Eskimos and bushmen, and of Nazi Germany.

We can discern at least seven well-defined role perceptions of the mentally retarded. Most of these roles are deviant ones. The relationship between these role perceptions and management of retarded people, and the design of their life space, though of crucial significance, is not always obvious. I will attempt to demonstrate how location, architecture, interior appointments, and day-to-day operating procedures of institutions will tend to form interrelated patterns (management models) that are consistent with various role perceptions of the retarded. (A similar attempt to relate psychiatric treatment approaches to schizophrenia to theoretical models can be found in Siegler and Osmond (1966).[12] For a discussion of Osmond's collaborative efforts with architect Izumi to design buildings for residents rather than for other architects, see Bayes (1967).[13]) Institutional models based on seven major role perceptions of the retarded person will be discussed.

The Retarded Person as Sick

One of the most prominent role perceptions of the retarded individual has been that of the sick person. The literature is replete with statements such as Fernald's (1915):[14] "The biological, economic and sociological bearings of feeble-mindedness have overshadowed the fact that it is fundamentally and essentially a medical question." A recent and unequivocal, more contemporary restatement of this role perception is contained in a very important document, the *Mental Retardation Handbook for the Primary Physician*.[15] In this work, mental retardation is repeatedly identified as a "disease" or an "illness."

When retarded persons are viewed as diseased organisms, residential facilities are structured on the (medical) hospital model. This model tends to have the following characteristics:

- The facility is administered by a medical hierarchy: the chief administrative officer (e.g., the superintendent) is a physician with a hierarchy of other physicians under him, and a hierarchy of nurses under them. Concern about authority lines tends to result in a tightly controlled perpendicular administrative structure rather than a flexible subunitized one.

- The residence is identified or even labeled, at least in part, as a hospital (e.g., "state hospital and school").

- Living units are referred to as nursing units or wards.

- Residents are referred to as patients, and their retardation is identified as being a "disease" that required a "diagnosis" and "prognosis."

- Resident care is referred to as nursing care.

- Case records are referred to as charts.

- Hospital routines prevail. For example, admission procedures may require days or weeks of "observation" and residence in an "infirmary," or similar unit prior to "diagnosis" and to assignment to regular living quarters. Daily routines may resemble hospital routines of rising, body inspections, sick call, charting, etc.; indeed, the daily schedule may revolve around the hinge of medication schedules. Dispensing of medication, in turn, may become the model for intake of nourishment, and for other "treatments" as well. Such other treatments, even if "administered" in the form of education, may be referred to as "dosages." Usually, there is at least moderate emphasis upon convenience of "nursing care."

- Concern with professional status symbols and status differentiation often encountered in a hospital atmosphere may be expressed by features such as presence of hierarchical staff lounges, showers, and private toilets. There may be separate vending machines for staff and "patients." Staff and residents rarely eat together. Caretaker personnel may wear uniforms. Even professional and semi-professional personnel may wear uniforms, coats of different colors, badges, nameplates with their degrees listed, and similar insignia of their role and rank.

- Nonmedical personnel may emulate the medical role, e.g., social workers and psychologists may wear white coats or jackets, and highly regarded professionals may be referred to as "doctor" even if they do not possess a doctorate.

- Resident management programs are referred to as "treatments" or "therapy;" e.g., recreation and work assignemnts may become recreational and industrial therapy. Even ordinary schooling may become educational therapy.

- Physicians, whether qualified or not, make decisions about nonmedical matters, e.g., residents' rights and privileges; visits; work assignments; discipline; inclusion in school, training, and other programs. Even if these decisions are made by nonmedical personnel, perhaps because of temporary or permanent lack of physician manpower, this may be perceived as delegation of medical authority, and as such is perceived and interpreted as undesirable and transient.

- Departments with the greatest affinity to medicine are given priority in program development, e.g., dentistry, orthopedics, and physical therapy may receive stronger support than behavior shaping, education, etc.
- Physical and medical techniques are more likely to be used in managing the bahavior of residents than other techniques. Thus, disturbed residents are more likely to be physically restricted or settled with drugs than to be counselled or trained; residents with seizures may be placed on anticonvulsant medication with little thought given to environmental manipulation of seizure-precipitating events or to educating the person to develop preventive behavior habits.
- There exists an excessive abhorrence of any chance or likelihood of injury to the resident. On the one hand, this is exemplified by lack of stairs and steps, sharp objects and corners, conventional electrical outlets, access to conventional hot water faucets, etc. On the other hand, it is exemplified by the presence of special features such as ramps, screening of radiators, and screened stairways (if any).
- A disease conceptualization of retardation tends to result in a management dilemma. On the one hand, such a conceptualization often results in pursuit of treatment hoped to result in cure; on the other hand, unless a "cure." is seen as likely, the management atmosphere is often permeated with hopelessness and treatment nihilism. In other words, the disease conceptualization tends to be correlated with inappropriate extremes of management attitudes.

The Retarded Person as a Subhuman Organism

The fact that deviant subgroups within a culture may be perceived as not fully human has long been recognized. To this day, large segments of our population deny full humanity to members of certain minority groups such as Blacks and American Indians. Retarded persons are particuarly likely to be unconsciously perceived or even consciously labelled as subhuman, as animal-like, or even as "vegetables" or "vegetative."

The literature of the field is richly endowed with labels alluding to the alleged subhuman nature of those who are retarded. The term "garden variety," widely used by professionals in the field to refer to cultural-familial retardation, has definite vegetative connotations.

Luther, in describing what appears to have been a severely or profoundly retarded child, denied the child's humanity as follows: "Eight years ago, there was one at Dessau whom I, Martinus Luther, saw and grappled with. He was twelve years old, had the use of his eyes and all his senses, so that one might think that he was a normal child. But he did nothing but gorge himself as much as four peasants or threshers. He ate, defecated and drooled and, if anyone tackled him, he screamed. If things didn't go well, he wept. So I said to the Prince of Anhalt: 'If I were the Prince, I should take this child to the Mola River which flows near Dessau and drown him.' But the Prince of Anhalt and the Prince of Saxony, who happened to be present, refused to follow my advice. Thereupon I said: 'Well, then the Christians shall order the Lord's Prayer to be said in church and pray that the dear Lord take the Devil away.' This was done daily in Dessau and the changeling died in the following year. When Luther was asked why he had made such a recommendation, he replied that he was firmly of the opinion that such changelings were merely a mass of flesh, a *massa carnis*, with no soul. 'For it is the Devil's power that he corrupts people who have reason and souls when he possesses them. The Devil sits in such changelings where their soul should have been!' ".[16]

Deutsch pointed out that by some peculiar twist of logic, mentally ill persons were often apt to be stripped of their human attributes, together with their rights and privileges as human beings. Obviously, it is even easier to dehumanize a person who never possessed much reason if one dehumanizes him who had reason but lost it. The idea that mentally afflicted persons lack sensory acuity; e.g., that they are insensitive to heat and cold, was popular into the mid-1800's (Deutsch 1949).[17] This myth resulted in their often being denied heat during the winter in the cold cells of institutions, and may well have contributed to the image of retarded persons as insensate vegetables.

To this day, retarded persons, like army recruits, are sometimes said to need "being broken" or tamed, like horses or wild beasts. Not long ago a magazine reader called for the " . . . sacrifice of mentally defective humans, or human vegetables . . ." to provide organ transplants and

". . . increase the intellectual betterment of mankind . . ." *(Atlantic Monthly)*.[18] Dehumanization of retarded persons is so accepted, even to this day, and even by workers in our own field, that we witness a public statement by a contemporary superintendent of a state institution referring to his retarded charges as ". . . so-called human beings . . . below what we might call an animal level of functioning . . ." *(Frontiers of Hospital Psychiatry*, 1968).[19]

The atmosphere and design of a residential facility can very clearly express an expectancy that the resident will behave in a subhuman fashion—no matter how vociferously the staff may deny adherence to dehumanizing attitudes. Such expectancies are implicit in any of virtually hundreds of dehumanizing practices encountered in institutions and enumerated by Vail (1967).[20] Some of the more common expectancies will be listed and briefly elucidated here.

- The perception of retarded persons as animals usually implies an expectation that they will behave in a primitive, uncontrolled fashion. Thus, the environment is designed to be "abuse-resistant," which implies measures such as:
  - Walls, floors, etc. made of indestructible material.
  - Unbreakable, shatterproof or wire-enmeshed glass in windows and partitions.
  - Installation of the sturdiest, most heavy-duty furniture and equipment.
  - Minimization of moving parts.
  - High ceilings with recessed or specially shielded or laminated light fixtures to minimize damage due to throwing of objects.
  - Soundproofing to muffle the sounds residents are expected to emit; this may even be installed in areas designed for persons quite capable of learning adaptive behavior.
  - Television sets protected by wire screens, recessed into protective housing, and/or placed above reach.
- A presumably subhuman individual is usually perceived as being potentially assaultive, destructive, and lacking in self-direction and constructive purpose; this necessitates restricting his movements both to control him more easily and to protect either the human from the subhuman, or one subhuman from another. This characteristically leads to a number of measures.
  - Locked living units.
  - Locked areas within living units. In the case of children or the physically handicapped, door knobs may be set high and above reach, or complicated release mechanisms may be installed. This permits staff to perceive the facility as "open" even though it is *de facto* locked.
  - Doors made from heavy material; bedroom doors can be locked only from the outside and often open outward rather than inward as in most homes or offices.
  - Barred windows. More sophisticated but equally effective are the reinforced window screens, or so-called security screening.
  - Outdoor play areas enclosed by either high walls or high, strong fences or by both. Often, these areas are quite small (and therefore, easier to control), and not sufficiently large, or equipped, for adequate exercise. Such small areas again permit the staff to engage in conscience-salving self-deception. I once inquired of a nurse whether the children in her locked living unit were ever dressed up and taken outdoors. She assured me that the children were dressed and taken for outdoor walks every day. The woman was not hypocritical; she was only rephrasing reality so that she could live with it. The reality was that these moderately to severely retarded ambulatory children did not leave the building confines for months, perhaps years, at a time. "Dressing" meant to put on more clothes than underpants and diapers; and "going for a walk outdoors" meant being turned loose in large groups with minimal supervision in a small outdoor enclave enclosed by high brick walls on two sides and high wire fences on the other two sides.
  - A fence or wall surrounding entire buildings or even an entire facility complex.
  - Segregation of sexes. Such segregation may assume absurd proportions when practiced with infants and children, or with aged retarded persons.

A typical programmatic, rather than architectural, expression of the subhuman view surrounds the "feeding" of residents. To this day, food and drink may be served in unbreakable tin reminiscent of prison riot films of the 1930s. Often no knives and forks are permitted. The latter measure also necessitates the service of special foods, such as finger foods or soft homogenized pap that can be spooned.

- Since the perceived subhuman is not believed to be capable of meaningful controlled choice behavior, he is permitted minimal control over his environment. This typically implies the following:
  - Switches controlling the lights of resident areas such as dayrooms, sleeping quarters, toilets, etc., are made inaccessible to residents by placement in staff control areas such as nursing stations, placement in locked cabinets, or keying (i.e., a key is required to turn a light on or off).
  - Water temperature in lavatories, showers, etc., is controlled by thermostats. The water flow itself may be controlled by staff by means of removable and portable handles.
  - Temperature, humidity, and air movement controls are locked or keyed.
  - Radiators are locked, recessed, or screened.
  - Residents are usually forbidden to carry matches or lighters.
- Perception of the retarded as animals implies an emphasis of efficient "keeping" of residents, rather than on interaction with personnel. Consequently, the environment is designed for efficient supervision.
  - Staff work behind isolating (protective?) partitions which keep out residents and perhaps even their sounds, but permit extensive or complete visual monitoring. A stated rationale here may be that isolation makes for greater efficiency in certain caretaker tasks such as visual supervision, recordkeeping, and administration of medications.
  - Residents sleep in large dormitories, with no or only low partitions between beds. Lights may burn even at night to facilitate supervision.
  - Staff location minimizes chances for interaction. For example, supervisory staff may be isolated in a separate building. Living units may be widely dispersed and removed so that real interaction between staff and residents is difficult to achieve. In one residential complex I have known, low staff interaction with residents was partially due to the fact that walking was both time-consuming and often not feasible due to bad weather, and driving was inconvenient because of lack of parking space near the residential units. Even staff meetings and in-service training activities can become an unconscious legitimization of noninteraction with residents.
  - There is much emphasis on use of drugs (chemical straight jackets?), rather than human interaction, to control and shape behavior.
  - The placement of residential centers far from population centers and towns can, in some cases, be a correlate of a "keeping" or "controlling" desire.
- Subhumans are perceived to "live like animals," i.e., to soil themselves and their habitat. This results in the design of an environment that can be cleaned easily, frequently, efficiently, and on a massive scale:
  - Walls and floors may be made of a material that is virtually impossible to "deface," i.e., scratch, soil, stain, etc., and that can be hosed down (as in a zoo); there may be drains in the floors of living areas.
  - Beds or bed stalls may be designed to be picked up by cranes and totally immersed in cleansing solutions.
  - Resident bathing facilities may be designed for efficient cleansing of large numbers of resident by small numbers of caretakers; there may be slabs, hoses, and mass showers, rather than installations which encourage residents to learn how to wash themselves.
- Typically, subhuman residents are either not expected to learn or to develop appreciably, or their growth potential is seen as so small as to be irrelevant, since it will never lead to complete humanization. In other words, the state of subhumanity is perceived as being essentially permanent. In consequence, the environment is designed to maintain a resident's level of functioning, but not to provide opportuniites for further growth and development.
- Animals have no rights; it follows that residents perceived to lack humanity are also perceived to lack certain rights. Among these are:
  - *The right to privacy.* Toilets and showers may lack partitions, curtains, or doors. Bedrooms often lack doors, not to mention that the bedrooms themselves may be lacking. Where doors exist, they almost always have window panes or so-called "Judas-windows" (complete with wire-enmeshed glass or peepholes). Private visiting space may be nonexistent.
  - *The right to property.* Institutionalized persons may have few or no possessions. Often they have no space to store possessions, or lack

ready access to such space or control over it. Residents are usually denied the privilege of locking up their possessions, carrying the key, and using it without restrictions. Children typically do not have use of personalized clothing, and children of the same size (sometimes of various sizes) may share the same pool of clothes. All of these points have implications for architectural design, especially for space allocations and selection of built-in furniture. Residents may be seen as not entitled to pay for their work, or to carry actual currency even if they do own money. "Poverty in a mental hospital is no less dehumanizing than in a slum . . . "(Bartlett, 1967).[21]

• • *The right to communicate freely.* There may be censorship of incoming and outgoing mail, although some forms of censorship may not be perceived as constituting censorship. Telephone usage may be severely restricted. Visiting is usually restricted for several weeks after admission.

• • *The right to individuality.* As described so well by Vail (1967),[22] residents are regimented and managed in groups, even where individual management might be feasible. For example, residents are mass-showered where education for individual showering is possible; residents may even be mass-toileted, which accounts for the fact that some living units have more toilet seats than would be needed for, say, an equivalent-sized college dormitory.

• The assumption that retarded persons lack esthetic sense is a subtle but important corollary of the subhuman view. This corollary results in the creation of unattractive residential living environments, since funds spent on beauty are seen as wasted. The drab, monotonous design and furnishing of residences (sometimes in contrast to staff living quarters) is usually a testimony to this view. Rarely does one see furniture that is both comfortable and attractive in lines and color, and even more rarely does the furniture reflect the mood and function of different living areas in an attractive fashion.

The degree to which retarded persons can appreciate beauty is really only one of two important issues involved here. The second important issue is that observers' (e.g., the public's or employee's) attitudes are shaped by the context in which retarded persons are presented to them. Even if intellectual limitation does impair the esthetic sense of retarded persons, to deprive their environment of beauty is likely to predispose an observer to view them as subhuman.

Staff sometimes claim that drabness is due to lack of funds but this is often untrue because much beauty can be provided at little or no cost. In my own institutional work, I recall trying to mount attractive pictures on walls of several children's drab living units. There was no support for this project from the institutional power echelons; nursing and housekeeping services objected to the "defacing" of the walls; and the pictures which actually got put up were pulled down (by personnel) within days.

A 1964 prospectus, written by the staff of an institution, contained the following instructions to an architect regarding the design of a new residence building for "trainable" retarded adults and young adults: "All interior wall surfaces shall be of a smooth material, and without wall projections other than those specifically stated. All thermostats should be protected with a guard to avoid tampering. Window areas shall be kept consistent with patient needs. Excessive window areas are not desirable. Consideration should be given to using shatterproof glass in patient areas. Door louvers in patient areas should be made of a steel material to withstand patient abuse. Mechanical and electrical equipment and controls throughout the building shall either be tamperproof or located outside the patient areas. Maximum water temperatures for bath and lavatories must be automatically controlled to eliminate the possibility of scalding. Switches in large patient areas shall be located on the outside of the rooms. A cubicle measuring 24" x 12" x 12" should be provided for each patient." While such instructions are not conclusive evidence that the instructors held the "subhuman" view rather than some other devaluing view of residents, they certainly appear to be consistent with such a view.

It cannot be emphasized too strongly that the alleviation of dehumanizing and other undesirable management practices is ultimately more a matter of attitude than of money. There have always been residential facilities that provide exemplary service at very low cost. Usually, such facilities were small, privately operated, and affiliated with religious organizations. On the other hand, one can point to public institutions in the United States where even generous funding and high staff-to-resident ratios have failed to change old practices. Eight attendants can look at 75 residents from behind an unbreakable glass shield as easily as one attendant can, and I have known an institution where this was the sanctioned pattern.

The Retarded Person as a Menace

Unknown events or objects, if alien enough, tend to arouse negative feelings in both man and beast. Man's history consists mostly of his persecution of fellow men who were different in features, skin pigmentation, size, shape, language, dress, etc., and it is apparent that man has been apt to see evil in deviance. It is not surprising that the retarded individual has often been perceived as a menace. He might be perceived as being a menace individually because of alleged propensities toward various crimes against persons and property; or he might be perceived collectively as a social menace because of alleged contribution to social disorganization and genetic decline.

The residential care model derived from the menace perception has much in common with the subhuman model. Certain features, such as segregation from the community, as well as segregation of the sexes, are likely to be accentuated. Since the menace model may ascribe a certain willfulness and evil intent to the retarded individual (in marked contrast to the medical model), an element of vindictiveness and persecution may enter into his management, and some of the protective features of the subhuman model may be omitted. Otherwise, residential features of both models have much in common.

The history of the menace model in the United States will be reviewed later in this essay.

The Retarded Person as an Object of Pity

One residential model is based upon the image of the retarded as objects of pity. People who have this image will often hold one or more correlated views:

- The retarded individual is seen as "suffering" from his condition, and there is emphasis on alleviation of this suffering.
- Although the person may be seen as "suffering", he may also be believed to be unaware of his deviancy.
- The retarded person is seen as "an eternal child" who "never grows."
- Being held blameless for his condition, the person is seen as not accountable for his behavior.
- The retarded individual is viewed with a "there but for the grace of God go I" attitude.

In residential services, the "pity image" will tend to be expressed in a paternalistic environment which both shelters the resident against injury and risk, and makes few demands for growth, development, and personal responsibility. Both these features may imply infantilization and lack of risks and environmental demands such as stairs, sharp edges, hot water, hot heaters, and electric outlets, as discussed previously.

The pity model has some features in common with the disease and subhuman models. However, there are important differentiating features. The pity model strives to bestow "happiness" upon the retarded person, usually by means of emphasis on programs of fun, religious nurture, and activity for its own sake. This, in turn, is likely to result in allocation of generous space and facilities for music, arts, crafts, parties, picnics, and worship (e.g., a chapel on the grounds).

It is no coincidence that the pity model shares features with the subhuman model: it has many similarities to Vail's (1967)[23] definition of the *"man-as-trivium"* (i.e., a human being who is not taken seriously or given importance) model of dehumanization.

The Retarded Person as a Burden of Charity

A person with a strongly moralistic conscience but with little genuine humanism is apt to perceive retarded individuals as objects of a sour charity. This attitude can best be compared to that of the Victorian age toward orphans. Since handicaps were seen in colonial America as a consequence of a stern providence meting out judgment for wickedness, a natural response to deformity and misfortune might be contempt rather than sympathy, and whatever help was rendered was "cold charity." (Deutsch, 1949).[24] The historical roots of state institutions were consistent with this view, since these institutions evolved, in part, from charitable homes for "paupers," orphans, vagrants, etc. (Bartlett, 1967).[25] Even the first institutions for retarded persons emphasized admission of children whose parents were unable to provide for their support (*Journal of Insanity*, 1852).[26]

The sour humanitarian may look upon a retarded resident as a kept object of (public) charity. Charity clients are seen as entitled to food and shelter, but not to anything which might seem luxuries, frills or extras. A residence based on this model will be austere and lacking in privacy, individuality, and opportunities to have personal possessions. The resident is expected to be grateful, and to work as much as possible for his "keep." A quotation from the Massachusetts report at the 1890 National Conference of Charities and Correction gives an example of the Victorian "burden of charity" view: "As to the State school, it recognizes the value only of such teaching, mental and manual, as shall develop the boy or girl and tend toward an honest and respectable life outside of the institution . . . It disapproves of extravagent or luxurious appointments in institutions, as foreign to the spirit of true charity. The inevitable weakening of character by life in institutions, the arrest of development, must be prevented, if possible, by some hardships and privations, such as these boys and girls would be sure to encounter in their own homes or those to which they would be sent." (*Reports from States*, 1890).[27]

Again, much of the physical environment implied by this model will be similar to that of the subhuman model; however, there are certain differentiating architectural and program implications. In a residence built on the charity model, there will be little emphasis upon segregation of residents from the rest of society. There will be a grim and unimaginative emphasis upon eventual self-sufficiency; and while there will be little stress upon environmental enrichment as a means of fostering development, education and training in the traditional handicrafts are likely to be strongly valued.

The Retarded Person as a Holy Innocent

Retarded persons, and possibly those persons with other handicaps as well, have occasionally been perceived as the special children of God. As such, they are usually seen as incapable of committing evil voluntarily, and consequently may be considered to be living saints. It may also be believed that they have been sent by God for some special purpose.

The role of holy or eternal innocents has been recognized in a number of cultures and eras. This role perception was reportedly prevalent among the American Indians and in medieval Europe. The concept of *"L'enfant du Bon Dieu"* embodies this image.

The holy innocent role has probably had a stronger influence on residential care thinking than is realized—albeit in a subtle way. The holy innocent was generally considered to be harmless, or was indulged much like a child. His presence may even have been valued, as it made the beholder feel a bit closer to heaven and to God. Thus, this role perception tended to inhibit the development of specially designated residential facilities, as the innocents were gladly accepted and integrated into the family and the heart of the community. A contemporary example is found in the Hutterite communities in the United States and Canada, studied by Eaton and Weil (1955).[28] In these communities, not one retarded individual had been institutionalized; instead they were accepted and integrated into the community life.

While the holy innocent perception inhibited the development of special residential placement, it did not prevent it altogether. If residential placement was achieved, however, it tended to be of a very special kind. It might involve placement of the person in a childlike role in a godly home; as a menial worker in religious communities such as monasteries; or as a worker in nursing homes or hospitals run by religious orders. One variant of this practice exists in the Belgian town of Geel where, for centuries, thousands of mentally handicapped persons have been boarded in an atmosphere of sheltered benevolence in ordinary homes and have the liberty of the city. The presence of a religious shrine to St. Dymphna—long believed to be (though no longer officially listed as) the patron saint of the mentally afflicted—gave rise to this practice.

Despite its good intentions, the holy innocent model has common elements with a dehumanizing ("man as other") perception described in Vail (1967).[29]

The Retarded Person as a Developing Individual

The developmental model takes an optimistic view of the modifiability of behavior, and usually it does not invest the differentness of the retarded person with strong negative value. Even if severely retarded, he is perceived as capable of growth, development, and learning. The developmental model is characterized by architecture designed to (1) facilitate and encourage the resident's interaction with the environment; (2) maximize interaction between staff and residents; (3) foster individuality, dignity, privacy, and personal responsibility; (4) furnish residents with living conditions which not only permit but encourage functioning similar to that of nonhandicapped community age peers.

In other words, the developmental model provides an atmosphere as similar as possible to that of a typical home, while introducing some additional features which either compensate for handicaps, and/or maximize the likelihood of developmental growth. Administratively, the developmental model will naturally tend to be a decentralized one, in contrast to the medical model, since a resident-oriented atmosphere demands that staff in immediate contact with residents must have flexibility and freedom to make rapid decisions.

Specific features of the developmental model might include:

- Homelike internal and external design.
- Colorful, light, bright, perceptually warm but diversified living units.
- Small, self-contained living units.
- Bedrooms for one or a few residents only.
- Family dining facilities
- Homelike appliances such as toilets, faucets, showers, baths, stoves.
- Nonstandardization of design and furnishings of living units.
- Windows of normal size, type, and placement.
- Live-in personnel.
- Plenty of space for individual possessions.
- Doors between rooms and areas.
- Curtains or doors for baths and showers, and toilets designed for private use.
- Homelike access to "controls" such as switches and thermostats. The idea here, as with other features, is that potentially objectionable behavior will be modified by interaction with staff, rather than being restricted by the design of the physical environment.
- Access to "risks," e.g., stairs, electrical outlets, hot water, etc. Again, the assumption is that residents will be trained to act adaptively, and that controlled risk is part of normal life.

The developmental model implies less of a perception of the retarded as deviant, while striving optimistically to minimize, or compensate for, what differentness there may be. The retarded are seen as more like than unlike others, to cite a cliché. Although particularly appropriate for children, the developmental model is equally meaningful when applied to adults.

O. R. Lindsley once said that our society is willing to spend money on the design of environments that maintain life, but not on those that maintain dignified behavior. Of all management models, the developmental one is probably most likely to provide the framework for a cathedral of human dignity.

Other Roles of Retarded Persons

In addition to the seven roles discussed above, there are other rather well-defined roles into which the retarded have frequently been cast. For instance, there is the role of the retarded as objects of merriment and ridicule, exemplified in an extreme form in their functioning as court fools and jesters. Though historically prominent, these roles will not be examined further because they have had little effect upon residential models.

The Meaning of a Building

That buildings have symbolic qualities is probably universally recognized. This symbolic quality is the meaning referred to here.

It was well expressed by Samuel Gridley Howe, probably the most significant and foresighted figure in the history of special education in the United States, although his role has not yet been fully appreciated. By 1866, when he gave the dedication address at the corner stone-laying of a new institution for blind persons in Batavia, New York, he had been instrumental in founding the early U.S. institutions for both blind and retarded persons, had been superintendent of the first public institution for retarded persons (in Massachusetts), and had already perceived and accurately defined most of the shortcomings under which institutions were to labor for the next 100 years. To capture fully the eloquence of Howe's statement on the language of architecture, I have excerpted several passages from his 1866 dedication address:[30]

"Language is of vast extent, and speech is only one of its powers. By speech and by print, men of our generation hold intercourse with each other. There are, moreover, some sorts of language by which the generations of men hold intercourse with other generations, and by which they converse across centuries and cycles of time. Among the various forms of language between generations, and between the ages, monuments hold a high place.

"As men and women unwittingly, and sometimes unwillingly, reveal their character, and even their secret motives of action, by the sort of language which they use, so the generations unwittingly reveal the prevailing ideas of the men who lived in them, by the works which they leave behind them.

Consider the pryamids of Egypt, and read the speech which they utter . . .

"It is, that the monarchs were absolute, selfish, cruel and short-sighted. That they built these vast monuments to preserve their fame from oblivion, and their bodies from disturbance. . . . The monuments tell us, moreover, that the people must have been ignorant, oppressed, and like 'dumb, driven cattle.'

"They tell us, that great multitudes of men and women were driven in from towns and villages, to toil and moil, and lift stones and carry sand for weeks and months; and when some had died and all were exhausted, then that fresh gangs were driven in to take their places.

"And so of smaller monuments, whether the triumphal arch, where the chained captive walks sadly behind the sculptured conquerors; or the storied column, with its winding procession of battles, assaults and sieges, leading up to the proud victor standing self-glorified on the top. And so of those which tell a better story—the aqueducts, the fountains, the bridges, the canals, the docks and the like.

"If we study the monuments which a generation built, and the kind of men in whose honor they raised statutes, we may learn much of the character of the people themselves.

"You are assembled to lay the foundations of a monument which will speak to future generations; and although what you grave upon the cornerstone, and what you put within it, should never be seen, the monument itself will talk to future generations; and what will it tell them?

"It will disclose that the physical condition of the human race in this country was imperfect and unfavorable and that there were born to this generation, and expected to be born in the next, . . . children, numerous enough to form a persistent class. That children of this class were not only loved and cherished by their parents and kindred, but also cared for by the public. That there was no Mount Taygetus here, on which to expose them, with other infirm folk, to perish or be devoured, but asylums into which they were gathered and nurtured.

"It will prove that the social and political union which here leagued three million people into one powerful State, was formed and maintained not only for defense against enemies, for common commercial interest, for great enterprises, for social prosperity and enjoyment, nor yet for mental culture and high civilization of the many, but also for the protection and care of the weak and infirm. That the State of New York, which could dig out a navigable river clear across her broad land—which had just armed and sent forth three hundred thousand sturdy soldiers to serve the common country and the cause of humanity,—that this great State, while holding on in her high career of material prosperity, and providing schools for all the children, took thought also, that not even the . . . little ones should be neglected.

"In such language will the building, whose foundation-stone you this day lay, speak to many generations in coming time.

"But, while thus noting with pleasure and even excusable pride, the humane impulses which prompt and which will carry forward the work, pardon me if I utter a word of warning:

"Good intentions and kind impulses do not necessarily lead to wise and truly humane measures.

"Nowhere is wisdom more necessary than in the guidance of charitable impulses. Meaning well is only half our duty; thinking right is the other and equally important half."

Buildings for the handicapped, like other buildings, can project many meanings. Certain of these meanings are of particular relevance to our discussion: the building as a monument, as a public relations medium, and as a medium of service.

The Building as a Monument

Buildings are often erected, consciously or unconsciously, as monuments. In mental retardation facilities, this is especially likely to be true of administration and medical treatment units. The monument may be to a governor; a famous man, a foundation donor, or donor dynasty; or an administrator or professional who may want to achieve identity or "immortality" through this monument-building. Common examples of the latter are the aged superintendent or administrator who wants to make one last, only, or major contribution before he retires or dies.

While such aspirations often result in genuine benefits to mankind, they can also pervert the consciously verbalized or officially defined purpose of the building. For example, in order to fulfill its function as a monument, the building may be erected in a locality not consistent with optimal program development; available funds may have been so plentiful as to result in a building that is either larger than optimal or overequipped; limitations of funds may result in a building so small as to require wasteful duplications and adjustments later; the ambitions of the initiator may require a free-standing building where an additional wing or floor on existing buildings would have been preferable; or the concepts which the initiator imposes upon the building plans may force future human services into undesirable and hard-to-remedy patterns. Examples of the latter are donations of facilities such as swimming pools, medical buildings, or churches. The existence of such facilities often makes it very difficult later to establish a pattern of increased use of the community for recreation, medical services, and church attendance. Similarly, an expensive new service building designed to serve large numbers of residents can become a great obstacle to reduction of an institution to a smaller size.

"Let us remember that our purpose is not to build costly monuments, at the expense of the taxpayer, to architects, legislators and governors or indeed to ourselves, . . ." (Kirkbride, 1916).[31]

The Building as a Public Relations Medium

A building, or an entire facility, can become a medium of public relations. While such a medium may produce desirable beneficial results in the long run, the public relations functions may also be irrelevant and even detrimental to the welfare of current residents.

- The building may function as an advertisement for the architect. There are many instances of widely acclaimed buildings which had serious functional shortcomings.

- Innovations in design may become means of aggrandizement or advancement to staff or superintendents. Real benefits of novel designs may be blown up beyond all proportion. Other widely hailed design innovations may later be recognized as gigantic and foreseeable errors. For example, one institution in the late 1950s erected a new showcase nursery in which the infants' cribs had solid (and expensive) marble sides and wire mesh fronts. Among other things, this obviously could lead to injuries, especially to children with seizures. Only a few years later, the cribs had to be rebuilt at great expense. This was hailed as another dynamic innovation rather than as rectification of a predictable blunder.

- A building may be a public relations tool for a governmental or political body. The building may be designed to win votes or good will, to gain power by providing employment opportunities and/or patronage, etc. Again, such buildings may do more harm than good. Erection of large institutions in isolated areas has often been prompted by such public relations (rather than service) considerations.

The Building as a Medium of Service

Finally, buildings may be designed truly and completely with service and function considerations in mind. In residential centers in the United States, such buildings are more likely to be encountered in private rather than public agencies. Too many of our public residential buildings and facilities reflect political, economic, and other considerations which have little to do with resident welfare.

The Focus of Convenience of a Building

Social norms demand that when a residence of some sort is constructed, we must pretend and proclaim that the building is designed for the convenience of the prospective residents. In reality, the building may be designed to serve the convenience of the builder. If residences are erected with public funds, the convenience of the community can easily become a primary consideration. If the prospective residents belong to a deviant subgroup that requires special management, then the building may be designed for the convenience of the "manager" (who is usually not a resident) rather than the "managed" resident.

The Convenience of the Architect

Some buildings are designed for the convenience of the architectural agent. Such buildings may have required the least imagination, planning, and work from the architect or engineer, while perhaps resulting in the largest profit to him. Many ill-designed, ill-constructed buildings and building complexes bespeak an utter disregard for the prospective resident. However, the building as a monument to the architect, though perhaps well-designed for external beauty and effect, may also fall into the "convenience of the architect" category if resident welfare is neglected.

The Convenience of the Community

The location of a large proportion of institutions in the United States was determined by economic considerations. Institutions were often placed in areas where jobs were needed, and placement became a very political matter. In many instances, institutions were located by the accident of land donations by job-hungry communities. Locations of this nature were not only ill-advised as far as the residents were concerned, but also inconvenient to their families. Furthermore, they resulted in professional and scientific isolation of the staff.

To locate any human service agency with the needs of the server rather than the served in mind is analogous to requiring people to eat in order to provide employment for cooks.

The Convenience of Staff

Many buildings, when entered, leave little doubt that staff convenience was paramount in the designer's mind. Characteristic elements may include the following:

- Caretaker stations providing maximal visual control over resident areas, while minimizing staff involvement; the glass-enclosed nursing station is a classical example.
- "Segregated" staff lounges to which staff withdraw for meals, coffee, rest, etc.
- Air conditioning for staff, but not for resident areas.
- Services such as classrooms, beauty shops, barber shops, and therapy areas that are located in the living units, saving staff the effort of dressing residents or escorting them to other buildings.

The Convenience of the Resident

If built for the welfare and convenience of residents, the location, size, type, and internal arrangement of most buildings and institutions in the United States would have been radically different from what they typically have been and are. Again, private facilities appear to have been more apt to be structured with the convenience of residents in mind.

II. The Evolution of Institutional Models in the United States

There is a riddle that holds a moral: if fish were intelligent creatures and had scientists and thinkers among them, what would be one of the last things they would probably discover? The answer to the riddle is supposed to be "water." After all, man discovered air only about 300 years ago.

Why do we have institutions at all? Why were they build, and why are they the way they are, and not some other way? Like fish, we have grown up with the fact that institutions exist and that they are places where retarded people are sent. Taking institutions for granted, we have perhaps failed to consider that there are societies that do not have them, or have them in quite a different form than the one we know. The last major attempt to interpret rather than merely recount the history of institutions for the retarded in the United States appears to have been made by Davies (1930).[32] His interpretations have been accepted essentially intact by subsequent workers and writers in the field. However, we must consider that as elegant as his interpretations were, they were very close to many historical events he tried to interpret. With another forty-five years of perspective behind us, it now seems appropriate to take a fresh look at history, and I will propose some new interpretations or elaborations in an attempt to gain further insight into the nature and origins of our institutional models. Particularly, I will try to demonstrate that attitudes toward deviancy generally have had much to do with the original rise of institutions for retarded persons in the United States, and with the way the more common residential models were shaped.

Making Deviant Individuals Undeviant

Around 1850, institutions for a number of deviant groups in the United States were founded for the purpose of making the deviant less deviant. The main means whereby this was to be accomplished was education. In effect, the argument was that deviant persons had to be congregated in one place so that expert and intensive attention could be concentrated on them. I must take issue with the now prevailing notion that the basic aim of the founding figures in our field was essentially and exclusively to reverse ("cure") retardation in children. From reading primary sources, I conclude that the goal was a combination of diminishing the intellectual impairment and increasing adaptive and compensatory skills of pupils so that they would be able to function at least minimally in society.

Wilbur (as quoted in *Journal of Insanity*) stated in 1852:

"We do not propose to create or supply faculties absolutely wanting; nor to bring all grades of idiocy to the same stardard of development or discipline; nor to make them all capable of sustaining, creditably, all the relations of a social and moral life; but rather to give to dormant faculties the greatest practicable development, and to apply those awakened faculties to a useful purpose under the control of an aroused and disciplined will.

"But great as are the benefits of education in ordinary cases, its achievements are still greater when, instead of increasing the capacities of the pupils, it substitutes capacities for incapacities; when it restores a class of human beings, now a burden to community, destitute of intelligence, degraded and miserable, to their friends and to society, more capable of development, under the ordinary circumstances of human development; nearer the common standard of humanity, in all respects; more capable of understanding and obeying human laws; of perceiving and yielding to moral obligations; more capable of self-assistance, of self-support, of self-respect, and of obtaining the greatest degree of comfort and happiness with their small means."[33]

The institution was seen as a temporary boarding school. After the child had mastered skills necessary in society, he was to be returned to his family and/or the regular schools. It certainly was not the intent of the pioneers that the institution should become a permanent home. For example, Samuel Gridley Howe said in 1851 of what is now Fernald State School: "This establishment, being intended for a school, should not be converted into an establishment for incurables." *(Journal of Insanity*, 1852).[34] "The early teachers of the feeble-minded jealously guarded their schools from the danger of becoming asylums. Admission was restricted to those classed as improvables . . . " (Johnson, 1898).[35] The institution was seen as " . . . a link in the chain of common schools—the last indeed, but still one necessary in order to make the chain embrace all the children in the state." (Howe, 1852).[36] The 1851 bylaws of the first mental retardation institution in New York, opened by Wilbur, are reported to have stated:[37]

"The design and object of the asylum . . . are not of a custodial character but are to furnish all the means of education to that portion of the youth of the state not provided for in any of its other educational institutions. . . . Those only will, therefore, be received . . . who are of a proper school-attending age, children between the ages of seven and fourteen, who are idiotic and who are not epileptic, insane nor greatly deformed."

The pioneers also made efforts to distinguish between more and less modifiable retarded persons. Generally, children with symptoms of severe brain injury and with multiple handicaps were not viewed as good prospects (e.g., Howe, 1848;[38] Seguin, 1870).[39] "The most favorable subjects for training, as a general thing, are those who enjoy good bodily health, who are free from epileptic and other fits, and whose heads are not enlarged" (Howe, 1852).[40] "The institution is not intended for epileptic or insane children, nor for those who are incurable hydrocephalic or paralytic, and any such will not be retained, to the exclusion of more improvable subjects" (Howe, 1852).[41] Seguin, after 30 years' experience, was reported to have said: "Idiots have been improved, educated, and even cured. Not one in 1000 has been entirely refractory to treatment, not one in 100 who has not been made more happy and healthy. More than 30 percent have been taught to conform to moral and social laws, and rendered capable of order, of good feeling, and of working like the third of a man. More than 40 percent have become capable of the ordinary transactions of life under friendly control, of understanding moral and social abstractions, of working like two-thirds of a man; and 25 to 30 percent have come nearer and nearer the standard of manhood, till some of them will defy the scrutiny of good judges, when compared with ordinary young men and women" (Seguin, 1898).[42]

It thus appears that only some retarded children were seen to be proper candidates for institutional education, and this education was to consist mostly of the transformation of the poorly socialized, perhaps speechless, and uncontrolled children into children who could stand and walk normally, have some speech, eat in an orderly manner, and engage in some kind of meaningful work. It should be kept in mind that perhaps this was equivalent to near-normality in a simpler society than ours today, and that from this fact may have grown the myth of the "curing" hopes of the early pioneers. However, translated to modern conditions, the pioneers appeared to have aspired to not much more than to what our best classes for severely retarded students aspire and frequently accomplish. The pioneers did not so much speak of making "idiots" normal as of "educating the idiot."

The early pioneers held to a number of other ideas and practices of interest to our topic. One of the country's first institutions was privately operated by Wilbur. It was a "school . . . organized on the family plan. The pupils all sat at the same table with the principal, and were constantly under the supervision of some member of the family in the hours of recreation and rest as well as of training. . . . It was the belief of the managers that only a relatively small number of inmates could be successfully cared for in one institution. It was deemed unwise to congregate a large number of persons suffering from any common infirmity" (Fernald, 1893).[43]

"Nearly every one of these early institutions was opened at or near the capitols of their various states, in order that the members of the legislature might closely watch their operation and personally see the need for the results of the instruction and training of these idiots" (Fernald, 1893).[44]

Indeed, the institutions were located in the very hearts of the community. The first public institution[45] in the United States, established in Massachusetts by an 1848 act, was located for a time in a large rented residence in South Boston *(Journal of Insanity*, 1852)[46] " . . . in a crowded neighborhood" (Kerlin, 1885).[47] Shortly thereafter, the first public institution of the State of New York was located in a " . . . large, spacious, airy, well arranged building on the Troy road, about two miles from the capitol . . ." *(Journal of Insanity*, 1852).[48] This building, too, was rented.

The rationale that the retarded can be and should be removed from society in order to be trained for return to society, though of very questionable validity, is still alive today. It is implemented, for instance, when groups of retarded adults are still placed in an institution for six months of training under some federal grant. However, it should be noted that the basic rationale for segregating deviant individuals for behavioral reshaping not only lacks adequate empirical foundation, but it is actually contrary to a vast store of empirical findings.

Essentially, making the deviant person undeviant implied a developmental model. Furthermore, residential schooling was seen not merely as a privilege or worthy charity, but a right of the retarded person and a duty of society. Again, Howe (1848)[49] was 100 years ahead of his time, and perhaps decades ahead of some of our contemporaries:

" . . . the immediate adoption of proper means of training and teaching idiots, may be urged upon higher grounds than that of expediency, or even of charity; it may be urged upon the ground of imperative duty. It has been shown, that the number of this wretched class is fearfully great, that a large part of them are directly at the public charge; that the whole of them are at the charge of the community in one way or another, because they cannot help themselves. It has been shown, that they are not only neglected, but that, through ignorance, they are often badly treated, and cruelly wronged; that, for want of proper means of training, some of them sink from mere weakness of mind, into entire idiocy so that, though born with a spark of intellect which might be nurtured into a flame, it is gradually extinguished, and they go down darkling to the grave, like the beasts that perish. Other countries are beginning to save such persons from their dreadful fate; and it must not longer be, that here, in the home of the Pilgrims, human beings, born with some sense, are allowed to sink into hopeless idiocy, for want of a helping hand.

"Massachusetts admits the right of all her citizens to a share in the blessings of education, and she provides it liberally for all her more favored children. If some be blind or deaf, she still continues to furnish them with special instruction at great cost; and will she longer neglect the poor idiot—the most wretched of all who are born to her, those who are usually abandoned by their fellows, who can never, of themselves, step up upon the platform of humanity—will she leave them to their dreadful fate, to a life of brutishness, without an effort in their behalf?

"The benefits to be derived from the establishment of a school for this class of persons, upon humane and scientific principles, would be very great. The school, if conducted by persons of skill and ability, would be a model for others . . . it would be demonstrated that no idiot need be confined or restrained by force . . . that they can be redeemed from odious and filthy habits, and that there is not one of any age, who may not be made more of a man, and less of a brute, by patience and kindness, directed by energy and skill. . . . Now, we claim for idiots a place in the human family."

The founding of the early institutions was accompanied by a pride, hope, and euphoria we can scarcely comprehend: "Let us now turn to the present: like Rome, we Americans can only boast of God-like men in our annals, and illustrious deeds on the historic page; as she had, we likewise are perhaps characterized by prominent faults, and by some compensating virtues. . . . Our eagles too have flown over a space equal to that which was traversed by those of Rome. To the Obelisks, and especially to the Cyclopean Coliseum we can show nothing equal or analogous.

But we possess a class of institution scattered throughout our country, to which Rome was a stranger, and through which we have attained an exalted position that she never reached, or even had the soul to aspire unto" (DeProspo, 1966).[50]

Protecting Deviant Individuals From Nondeviant People

History appears to have wronged the founding fathers in ascribing to them the hope of "curing," large numbers of the retarded. Our texts also seem to be partially mistaken in judging the early institutions to have failed to reach their objectives. Many residents were much improved under the tight and well-planned training regimens of the pioneers, and a substantial proportion of trainees did, indeed, return to the community.

About 26 percent of residents discharged in Connecticut were believed to be self-supporting (Knight, 1879).[51] In Kentucky, in 1884 alone, about 3 percent of the residents of the state institution were placed into community employment (Kerlin, 1885),[52] and about 19 percent of all new admissions were eventually discharged as self-supporting (Rogers, 1888).[53] "The experience of the past thirty years proves that, of those who are recieved and trained in institutions, 10 to 20 percent are so improved as to be able to enter life as breadwinners; that from 30 to 40 percent are returned to their families so improved as to be self-helpful, or at least much less burdensome to their people" (Kerlin, 1888).[54]

At Glenwood (Iowa), 68 of 195 residents were separated between 1885 and 1887, a 10–20 percent of the residents appeared to attain eventual self-sufficiency in the community (Powell, 1887).[55] "All of our schools for the feeble-minded have succeeded in sending out a goodly number of persons who are bearing bravely their share of the burden of life" (Rogers, 1888).[56]

There were, however, four problems:

- There were bound to be failures with a certain proportion of residents.

- For every resident successfully discharged, the statistical probabilities (due to the law of regression) were that his replacement would be less successful. It is hard to improve upon successful habilitation; it is much easier to fail thereafter.

- Many residents who could have been partially habilitated had no place to return to, and thus, after some years, their continued presence reduced turnover. Seguin referred to this as early as 1870 as a " . . . paternal, not yet legalized, arrangement,"[57] and Fernald (1893)[58] later described it as follows: "In the course of a few years, in the annual reports of these institutions we find the superintendents regretting that it was not expedient to return to the community a certain number of cases who had received all the instruction the school had to offer. . . . It was found that only a small proportion . . . could be so developed and improved that they could go out into the world and support themselves independently. A large number, as a result of the school discipline and training, could be taken home where they became comparatively harmless and unobjectionable members of the family, capable, and under the loving and watchful care of their friends, of earning by their labor as much as it cost to maintain them. But in many cases the guardians of these children were unwilling to remove them from the institution, and begged that they might be allowed to remain where they could be made happy and kept from harm. Many of these cases were homeless and friendless, and, if sent away from the school, could only be transferred to almshouses where they became depraved and demoralized by association with adult paupers and vagrants of both sexes. It was neither wise nor humane to turn these boys and girls out to shift for themselves. The placing of these feeble-minded persons always proved unsatisfactory. Even those who had suitable homes and friends able and willing to become responsible for them, by the death of these relatives were thrown on their own resources and drifted into pauperism and crime. It gradually became evident that a certain number of these higher-grade cases needed life-long care and supervision, and that there was no suitable provision for this permanent custody outside these special institutions."

- Many people, as evident in our textbooks, had misunderstood the objectives of the pioneers in expecting complete and rapid cures in large numbers, and interpreted any lesser accomplishment as tantamount to failure.

At any rate, with the perceived failure of the institution as a school, and the inability of many adult residents to adjust to the community, ideologies changed between about 1870 and 1880. Developmental attitudes degenerated into pity and charity, and as they did, the residential model changed from a developmental one to a pity model. The idea grew that the retarded should be viewed as innocent victims of fate or parental sin, and that instead of schooling, loving care and protection should be bestowed upon them.

The term "school" began to disappear from the names of institutions, being replaced by the term "asylum." For example, in 1893, the "Custodial Asylum for Unteachable Idiots" was founded in Rome, New York. "Give them an asylum, with good and kind treatment; but not a school," Governor Butler of Massachusetts[59] is quoted as saying. "A well-fed, well-cared for idiot, is a happy creature. An idiot awakened to his condition is a miserable one. . . . It is earnestly urged that the best disposal to be made of this large class of the permanently disable is to place it in custodial departments of institutions for the feeble-minded persons, in buildings judiciously remote from the educational and industrial departments, but under the same merciful system that inspires hope and help for the lowest of humanity, and under a broadly classified administration that will admit of the employment of the so-called moral idiot, thereby diminishing greatly the burden to the charitable and the taxpayer" (Kerlin, 1888).[60] "The question of unimprovability then being once established, the only practicable thing to do is to furnigh a home where, amid cheerful surroundings, in accordance with the state of our Christian civilization, and in a manner consistent with an age of practical economy, the mediocre imbecile may lead a happy, harmless, and measurable useful life in assisting to care for his fellows" (Rogers, 1888).[61] "They must be kept quietly, safely, away from the world, living like the angels in heaven, neither marrying nor given in marriage" (Johnson, 1889).[62]

Illinois erected a "hospital building" for custodial purposes in 1885; a custodial department was installed in Iowa the same year; Connecticut made its first appropriation for such a building in that year and Pennsylvania built such a building in 1886 (Kerlin, 1886).[63]

The institution was no longer to be a school, but a shelter, an asylum of happiness, a garden of Eden for the innocent. What doubt there may have remained was largely dispelled by the close of the century: "Slowly but surely the conviction has become general, especially among the trustees and officers of institutions, that admission as a pupil of the training school should be but the first step to permanent care; that, with a few exceptions, so few that they may be disregarded in establishing a policy, all the pupils of the school, from the lowest to the highest grade, ought to be permanently retained in the safe, kindly, maternal care of the state. The above conviction is held by all who have expressed themselves publicly within the last few years in this country, excepting a few persons whose pecuniary interests seem in conflict with such a theory. It has been acted upon by the legislature of many states, whose laws have been changed by removing from the institution code the age limit of retention, and in some cases of acceptance. . . . A belief in the necessity of permanent care of all this defective class is professed by the superintendent of every state school for the feeble-minded in the United States" (Johnson, 1898).[64]

The protective residential model emphasized benevolent shelter, but it bore the seeds of three dangerous trends: (1) isolation, (2) enlargement, and (3) economization.

Isolation

The retarded person was to be moved out of society, in order to spare him the stresses he was believed incapable of bearing, and to provide him with protection from the persecution and ridicule of the nondeviant. The idea that he must be protected from society, rather than vice versa, was well expressed by Kerlin in 1884:[65] "The general grounds of the institution should be hedged or fenced to keep off improper intrusion but be freely used by the inmates for walking exercise and work." H.B. Wilbur in 1879[66] recommended that institution grounds be fenced " . . . for the privacy of the inmates." Thus, institutions began to be removed from population centers and located in pastoral surroundings.

Writers of the period waxed rhapsodic over their own benevolence and drew an idyllic pictures of the new trend: "Here and there, scattered over the country, may be 'villages of the simple,' made up of the warped, twisted, and incorrigible, happily contributing to their own and the support of those more lowly,—'cities of refuge,' in truth; havens in which all shall live contentedly, because no longer misunderstood nor taxed with extractions beyond their mental or moral capacity" (Kerlin, 1885).[67] " . . . God's innocent ones . . . " (Kerlin, 1886)[68] were to reside " . . . in harmony with the spirit of a progressive age and a Christian philantropy" (Rogers, 1888)[69] in " . . . noble institutions of the times—those temples sacred to the restoration of fallen humanity, nearer Christ in His work than half the shrines dedicated in His name . . . " (Greene, 1884).[70] These institutions were beind . . . sustained . . . by an abounding popular sympathy . . . " (Kerlin, 1886).[71]

If the institution was to be a garden of Eden, it needed lands and gardens, and sure enough, an emphasis on gardening and farming developed. Thus, Osborne in 1891[72] stated: "Ample acreage (not less than one acre per patient) will be provided for the proper seclusion of defectives from the stare of the idle and curious . . . " (Kerlin (1884)[73] described the Connecticut institution as being ". . . beautifully situated on a large farm . . . ," and by 1915, Schlapp[74] was able to say: "Most of our institutions are beautifully situated in the country." To this day, the phrase "happy farm" (much like "funny farm") is occasionally heard in reference to state hospitals and institutions for retarded persons.

Enlargement

The idea developed that if there was to be special protective care, it would be advantageous to congregate larger numbers of residents together. If institutions had to serve both an educational and custodial function, and if, for several decades, the educational department of an institution turned over more graduates to the custodial department than the latter discharged (usually because of death), then it followed that institutions were under multiple pressure to grow. And grow they did. For instance, in Massachusetts, the first call by the trustees for substantial enlarging of the institution came in 1881, and this enlargement was to accommodate not only the "improvables" but also the "unimprovables" (Kerlin, 1885).[75] In Ohio, the transition from the smaller educational to the larger custodial institution was aided greatly by a disastrous fire in the year 1881. "Perhaps no trouble weighed more heavily upon the management than an effort to prevent the reconstruction of the building as an educational institution for feeble-minded children." The issue was "squarely met," and $400,000 was appropriated to construct the ". . . best built and best appointed institution in the world . . ." for 600 residents (Kerlin, 1885).[76]

It is fascinating to trace the enlargement of institutions, and the fitful process of rationalization that accompanied it. First, to make room for rationalizing the enlargement, the pioneers' ideal of the small institution had to be destroyed. Paradoxically, this was done by accusing small institutions of "hospitalism": "It is the small institution against which may be pronounced the objection of moral hospitalism. The large, diffuse, and thoroughly classified institution is another affair, and can be to its wards and employees as cosmopolitan as a city" (Kerlin, 1884).[77] "The growth of our institution to the proportion of a village, as earnestly urged by the superintendent, divides the board. The conservative element, which from the beginning has considered an institution of 50 or 60 children as the ideal, is still struggling against the inevitable. But thanks to Ohio, which continues to show us the way, in which all progressive States will follow . . ." (Kerlin, 1885).[78]

The irresistible trend toward enlargement was, at first, rationalized as being for the benefit of the resident. We detect the sentiment, present perhaps in all generations, that it is better for the deviant if they associate with their own kind: "We find that we must congregate them to get our best results. It is only from a large number that we can select enough of any one grade to make a group or class. . . . In order to have companionship, the most necessary thing in the education of all children, we must have large numbers from which to make up our small classes of those who are of an equal degree of intelligence" (Knight, 1891).[79] "I believe that a large state institution is the best place for the feeble-minded or idiotic child" (Johnson, 1901).[80]

Others were more candid and advocated enlargement as a means of reducing cost, and during the pity period, the first arguments for the need of inexpensive care were heard. Wilbur had warned in 1880: "It will be readily seen that the cost of maintenance in such an establishment is a more important one than in the case of the educational institutions" (Kerlin, 1885).[81] In about 1887, an act was passed in Pennsylvania which raised the number of state-supported residents from 400 to 500 while reducing the permissible per capita expenditure from $200 to $175 (Kerlin, 1888).[82] "We have proved too, that in large institutions we can give employment to those adult imbeciles who are beyond what we call the 'school age' . . . A superintendents of institutions we are working out new methods in management, in economy and education . . . " (Knight, 1895).[83]

Rogers, in 1888,[84] took one last look over his shoulders, as he and the field plunged ahead: ". . . to those who fear the growth of large and unwieldy institutions we only say that matters of that kind must be settled by the communities which are responsible for them. If this danger appears, stop the growth and build another institution, but do not warp the usefulness of any by a narrow comprehension of its functions."

By 1893, Fernald[85] had observed a phenomenon familiar to us all: "Successive legislatures have been ready to enlarge existing institutions when they would not grant appropriations for establishing new ones." Thus, institutions changed from small intimate homes, for children counted in the dozens, to huge facilities for thousands of residents, and in 1893, Fernald could already refer to institutions as ". . . these immense households."

Economization

Initially, as a constructive substitute for educational activities, increasing emphasis was placed on the work of the residents. Purportedly, the work was ". . . not for the value of the work itself, but for its value to the child" (Kerlin, 1885).[86] Kerlin quoted from a Massachusetts report:[87] "The work-shop where several such industries are carried on provides occupation and relief from the depressing ennui of idleness, and at the same time fosters physical development and intellectual growth . . . With their daily tasks, their feeble minds directed, the time taken up in work or exercise, their days are spent in safety, pleasantness, and peace," he quoted from the First Annual Report of the Trustees of the New York State Custodial Asylum for Feebleminded Women,[88] ". . . the farm thus serving to provide healthful and attractive occupation for the stronger members of the institution . . ." *(Reports from States*, 1896).[89]

As usual, however, noble sentiments gave way to utilitarian practices, and the economic value of work to the institution began to be stressed: ". . . the trained capacities of the stronger shall be made available for the aid of the weaker and for the diminution of public charge." (Kerlin, 1886).[90]

The economic emphasis, in the rural America of about 1880, implied adoption of agricultural pursuits, which, in turn, required land. The trend toward farming, combined with the desire to protect retarded persons, resulted in locating institutions in isolated rural areas. For instance, establishment of the first farm colony (the "Howe Farm") in Massachusetts in 1881 (Kerlin, 1885;[91] Fernald, 1902)[92] became the occasion for moving residents from the institution in the heart of Boston out into the country, and to the periphery of society. Kansas opened its first state institution in 1881 near Lawrence, seat of the University, and Leavenworth, one of the important crossroads of the West. Three years later, the institution was moved far away onto a farm near Winfield (Kerlin, 1885;[93] *Status of the Work*, 1886)[94] because the land had been donated, and in order to deal a blow to the University.

Vail (1967)[95] has classified the pity attitude as a special and subtle type of dehumanization. This may have been very insightful, since once the developmental attitude changed to pity, pity lasted only about 10-20 years, and was followed by a long period of brutalization. In our society, pity is usually extended to a person who is perceived as suffering. However, much of suffering, as we conceptualize it, implies that the sufferer should receive some kind of help, which may consume the time, money, emotional involvement or efforts of others. Suffering, by its very nature, thus makes a demand on a conscience developed in the Judeo-Christian tradition. This demand, in turn, may create resentment, especially if the sufferer does not "get well," and resentment may lead to brutalization. The fact that one of the most influential social organizations between 1874 and 1917 was the National Conference on Charities and Correction is of relevance, as it shows that the bestowers of pity and the controllers of menace had much in common.

Protecting Nondeviant Individuals from Deviant People

Preceding and paralleling the education and pity periods, there had existed a current of negative attitudes toward retarded persons. These attitudes, the three dangerous trends mentioned in the last section, and a new conceptualization of the retarded individual, combined to shape a new institutional model which is essentially the model embodied in most of our large, public institutions today.

The Early Indictment

The image of the retarded person as a social menace grew in a subtle way. As early as the mid 1880s, the alarm was sounded: "But the State, adopting as its policy the protection in institutions of the defective classes, acquires a right of inquest into the causes generating this tremendous burden to the thrifty taxpayer, who must be protected from the rapacious social ills which deplete his own strength" (Kerlin, 1884).[96]

An early president of the National Conference on Charities and Correction was later quoted by Wilmarth (1902)[97] as having said: " 'My child, your life has been one succession of failures. You cannot feed and clothe yourself honestly: you cannot control your appetites and passions. Left to yourself, you are not only useless, but mischievous. Henceforth I shall care for you.' "

"Is there anything more worthy the thoughtful attention of the statesmen of our land than to improve our methods of support of the weak ones so that we may add to it the needed element 'control'?" (Johnson, 1903).[98]

" . . . Can it be deemed wise, either for society or the defective himself, to turn him loose after some years of training to make his fight for existence on his own behalf? . . . No amount of moral training during his school life can render him capable of judging points of morality for himself or make him proof against temptations to which his natural tendencies incline him to yield. The end will almost inevitably be that he will drift back into the care of the state, but through the gates of crime" (Dunphy, 1908).[99]

"What in the beginning was a philanthropic purpose, pure and simple, having for its object the most needy, and therefore naturally directed toward paupers and idiots, now assumes the proportions of socialistic reform as a matter of self-preservation, a necessity to preserve the nation from the encroachments of imbecility, of crime, and all the fateful consequences of a highly nervous age" (Barr, 1899).[100]

Fernald (1915)[101] summarized the trend as follows:

"During the last decade four factors have materially changed the professional and popular conception of the problem of the feeble-minded.

"1. The widespread use of mental tests has greatly simplified the preliminary recognition of ordinary cases of mental defect and done much to popularize the knowledge of the extent and importance of feeble-mindedness.

"2. The intensive studies of the family histories of large numbers of the feeble-minded by Goddard, Davenport, and Tredgold have demonstrated what had hitherto only been suspected, that the great majority of these persons are feeble-minded because they come from family stocks which transmit feeble-mindedness from generation to generation in accordance with the laws of heredity. Many of the members of these families are not defective, themselves, but these normal members of tainted families are liable to have a certain number of defectives among their own descendants. The number of persons who are feeble-minded as a result of injury, disease, or other environmental conditions without hereditary predisposition is much smaller than had been suspected, and these accidental cases do not transmit their defect to their progeny.

"3. The cumulative evidence furnished by surveys, community studies, and intensive group inquiries have now definitely proved that feeble-mindedness is an important factor as a cause of juvenile vice and delinquency, adult crime, sex immorality, the spread of venereal disease, prostitution, illegitimacy, vagrancy, pauperism, and other forms of social evil and social disease.

"4. Our estimates of the extent and the prevalence of feeble-mindeness have been greatly increased by the application of mental tests, the public school classes for defectives, interpretation of the above-mentioned antisocial expressions of feeble-mindedness, and the intensive community studies. Goddard believes that at least two percent of school children in the first five grades are mentally defective. It is conservative to say that there are at least 4 feeble-minded persons to each 1,000 of the general population.

"There are reasons for believing that feeble-mindedness is on the increase, that it has leaped its barriers, so to speak, as a result of changed conditions of civilization."

One might add here that a fifth point was the belief that the retarded were reproducing at a more prolific rate than the nonretarded, and might therefore "outbreed" the latter.

The Peak of the Indictment

As time passed, the social indictment of the retarded grew more direct, severe, and shrill. Barr said: "Of all dependent classes there are none that drain so entirely the social and financial life of the body politic as the imbecile, unless it be its close associate, the epileptic" (1902).[102]

Butler (1907)[103] added: "While there are many anti-social forces, I believe none demands more earnest thought, more immediate action than this. Feeble-mindedness produces more pauperism, degeneracy and crime than any other one force. It touches every form of charitable activity. It is felt in every part of our land. It affects in some way all our people. Its cost is beyond our comprehension."

"When we view the number of the feeble-minded, their fecundity, their lack of control, the menace they are, the degradation they cause, the degeneracy they perpetuate, the suffering and misery and crime they spread—these are the burden we must bear" (Butler, 1915).[104]

"For many generations we have recognized and pitied the idiot. Of late we have recognized a higher type of defective, the moron, and have discovered that he is a burden; that he is a menace of society and civilization; that he is responsible to a large degree for many, if not all, of our social problems" (Goddard, 1915).[105]

Bullard (1910),[106] in the strongest statement of indictment of retarded women, warned: "Girls of the classes described must be cared for by the state . . . There is no class of persons in our whole population who, unit for unit, are so dangerous or so expensive to the state. This excepts no class, not even the violently insane. They are much more dangerous and expensive than the ordinary insane or the ordinary feeble-minded or the ordinary male criminal." He (1910)[107] added: "There is probably no class of persons who are more fitted and more apt to spread disease and moral evil than these girls," and "One evil girl may corrupt a whole village." And in 1915 he said: "A single feeble-minded girl among a group of young boys becomes a plague-spot, the consequences of which are frightful."[108]

So while retarded males were seen as a "menace of the greatest magnitude," females were seen as even more dangerous, if this is possible: "It is certain that the feeble-minded girl or woman in the city rarely escapes the sexual experiences that too often result in the birth of more defectives and degenerates" (Fernald, 1912).[109] "Imbecile girls and women everywhere are an easy prey to the wiles and lust of brutal men, . . ." (Carson, 1898).[110] "Feeble-minded women are almost invariably immoral, and if at large usually become carriers of venereal disease or give birth to children who are as defective as themselves. The feeble-minded woman who marries is twice as prolific as the normal woman" (Fernald, 1912).[111]

Fernald was one of the strongest indicators: "And pauperism breeding other paupers, what is it but imbecility let free to do its mischief? . . . The tendency to lead dissolute lives is especially noticeable in the females. A feeble-minded girl is exposed as no other girl in the world is exposed" (Fernald, 1893).[112] Later, in 1904,[113] he said: "It is well known that feeble-minded women and girls are very liable to become sources of unspeakable debauchery and licentiousness which pollutes the whole life of the young boys and youth of the community. They frequently disseminate in a wholesale way the most loathsome and deadly diseases, permanently poisoning the minds and bodies of thoughtless youth at the very threshold of manhood. Almost every country town has one or more of these defective women, each having from one to four or more illegitimate children, every one of whom is predestined to be defective mentally, criminal, or an outcast of some sort.

"The modern American community is very intolerant of the presence of these dangerous defectives with the desires and passions of adult life, without control of reason and judgment. There is a widespread and insistent demand that these women be put under control . . ."

"The adult males become the town loafers and incapables, the irresponsible pests of the neighborhood, petty thieves, purposeless destroyers of property, incendiaries, and very frequently violators of women and little girls" (1904).[114]

"The social and economic burdens of uncomplicated feeble-mindedness are only too well known. The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. The great majority ultimately become public charges in some form. They cause considerable sorrow at home and are a menace and danger to the community . . . Every feeble-minded person, especially the high-grade imbecile, is a potential criminal, needing expression of his criminal tendencies. The unrecognized imbecile is a most dangerous element in the community . . . It has been truly said that feeble-mindedness is the mother of crime, pauperism and degeneracy. It is certain that the feeble-minded and the progeny of the feeble-minded constitute one of the great social and economic burdens of modern times" (Fernald, 1912).[115]

The peak of the indictment was reached between 1908 and 1915 and was embodied in three important documents:

- The 1908 British Royal Commission Report which became very influential:

"The evidence points unmistakenly to the fact that mentally defective children often have immoral tendencies; that they are greatly lacking in self-control; and moreover are peculiarly open to suggestion, so that they are at the mercy of bad companions.

"Many competent observers are of the opinion that if the constantly or recurring fatuous and irresponsible crimes and offenses of mentally defective persons are to be prevented, long and continuous detention is necessary. The experience of the prison authorities fully confirms this opinion. From the earliest age, when they appear before the magistrates as children on remand or as juvenile offenders, until and throughout the adult period of their lives, the mentally defective, at first reprimanded and returned to their parents, then convicted and subjected to a short sentence and returned to their parents, and then later continually sentenced and resentenced and returned to their parents or friends until, for crimes of greater gravity, they pass through the convict prisons, are treated, as this reiterated evidence shows, without hope and without purpose, and in such a way as to allow a feeble-minded progeny which may become criminal like themselves. This, as has been said, is an 'evil of the very greatest magnitude.' The absolute and urgent necessity of coping with it is undeniable" (Davies, 1923).[116]

- In 1912, Fernald[117] wrote a damning indictment of the retarded in his famous address on "The Burden of Feeble-Mindedness," a burden he had earlier (1893)[118] called "disgusting."
- Bullard (1910)[119] wrote an incredible diatribe about the particular immorality and menace of retarded women.

In weighing the influence of some of those quoted in preceding and subsequent sections, let the reader be reminded that the following 25 persons had been, or became, president of what is now the American Association of Mental Deficiency: C. T. Wilbur, Stewart, Powell, Fish, G. H. Knight, Carson, Rogers, Kerlin, Osborne, Wilmarth, Barr, Dunlap, Johnson, Polglase, Murdoch, Smith, Bullard, Goddard, Emerick, Watkins, and Anderson; Bernstein, Fernald, Johnstone, and Wallace held the presidency twice. Johnson had also been president of the National Conference on Charities and Correction, as well as its general secretary for many years. This latter organization was perhaps the major vehicle of the indictment, since it was a major forum for indictment speeches and papers, and since it encompassed those professionals most intimately concerned with social processes, such as social workers, sociologists, legal and law enforcement personnel, psychiatrists, psychologists, public health and immigration workers, and officials from all levels of government.

Dehumanizing and Brutalizing Elements of the Indictment

The indictment contained some ominous notes. Streeter (1915)[120] said: ". . . in feeble-mindedness lies the tap root of most of our social problems; the only effective radical way to deal with these problems, is to strike at this tap root with the strong ax of prevention." Barr (1902a;[121] 1902b),[122] a very influential past president of what is now the American Association on Mental Deficiency, issued an "Imperative Call of Our Present to Our Future," followed by an address entitled "The Imbecile and Epileptic Versus the Taxpayer and the Community." The title of a book by Crookshank in 1924 was enough to drive a shudder down anyone's spine: *The Mongol in Our Midst.*[123]

Where we, today, speak of combatting mental retardation, as in the President's Panel *National Plan to Combat Mental Retardation*, phrases with menacing overtones were used in the alarmist period, as when Johnson (1898)[124] spoke of "stamping out" idiocy and imbecility. That this was more than a figure of speech became clear two years later, when he stated: "I do not think that, to prevent the propagation of this class it is necessary to kill them off or to resort to the knife; but, if it is necessary, it should be done" (Johnson, 1901).[125] Alexander Johnson, past president of the National Conference on Charities and Correction, and of what is now the American Association on Mental Deficiency, was one of the most influential figures in the social action field of the era.

One gentleman from Massachusetts, in 1885, was reported to have called for the same solution to the problem of feeble-mindedness as that which has been "applied theoretically and also practically to the Indian question" (Conference on Charities and Correction, 1888),[126] and Taft (1918)[127] ominously referred to a ". . . final . . . solution," a term that would come into its full meaning 20 years later.

In any society that places high value on intelligence and achievement, there is probably a predisposition to brutalize and dehumanize the inadequate deviant person. When the deviant person is seen as not only inadequate but also as a menace, latent dehumanization becomes overt. It therefore should not surprise us that during the alarmist period, the retarded were dehumanized in both word and deed.

Analogies based on examples from the animal, vegetable and mineral world are sometimes offered to explain a point about retardation. Such analogies are ill-chosen at best; at worst, they reveal that the person using such an analogy perceives the retarded person as subhuman. Some examples of ill-chosen word pictures used during the indictment period follow. Kerlin (1884)[128] said of a retarded person: "With his great luminous, soft, jet eyes, he reminds one of a seal." Fernald (1915)[129] observed: "We now have state commissions for controlling the gypsy moth and the boll weevil, the foot-and-mouth disease, and for protecting the shell-fish and wild game, but we have no commission which even attempts to modify or control the vast social, moral and economic forces represented by the feeble-minded persons at large in the community." Davenport moved from "unfit animal strains" to "weak strains" to the "feeble-minded" in the space of two sentences (quoted in Fernald, 1915).[130]

Simultaneous reference to animal breeding and to reproduction of the retarded abounded. Brewer (1895)[131] referred to ". . . this breed of men" being a ". . . poor breed of stock." Barr (1902)[132] had this to say: "We are very careful as to the breeding, inbreeding, or non-breeding of our flocks and herds, and beasts of burden; but we allow epileptics and irresponsible imbeciles to taint pure stock or to reproduce their kind unmolested without intervention." The important role of a national association of cattlemen in the study of prevention of retardation is noteworthy and will be touched upon again later in this essay.

Wines (1889;[133] also quoted by Bicknell, 1896)[134] said about retarded workers: "Many of them are capable of being made useful to a large extent even though they may be unable to talk. I have seen idiots who were useful on a farm, for instance, who could not speak a word. Is not a mule valuable on a farm? Yet he cannot talk." In describing a retarded woman chained by the neck to a dog's running wire in the yard, he denied that she was suffering because "she was a mere animal, well cared-for as an animal."

Nosworthy (1907)[135] probably expressed latent sentiments most honestly when, in all seriousness, she raised the question whether the feeble-minded constitute a separate species, and then designed a study to investigate this matter.

Humans can be dehumanized even below the animal and vegetative level, as when they are called "waste products" (Barr, 1902;[136] Anderson, 1918)[137] or "by-products" (MacMurchy as quoted by Murdoch, 1909;[138] Southard, 1915).[139] Southard, who used this term, continued to ask: ". . . it becomes a question with us, what to do with these waste materials."

Concern with Prevention

Retardation was clearly considered to be hereditary. "It is possible that a real eugenic survey of a given locality might show that 90 percent of the feeble-mindedness in that locality was contributed by 5 percent of the families in that community." (Fernald, 1915).[140] "Degeneracy, once permitted to invade a lineage, can never be wholly eradicated; lessened materially, and even reduced to a minimum it may be, but sooner or later, in one generation or another, a defective is bound to appear . . . There are at least 328,000 mental and moral defectives at large, perpetrating, unrestrained, the defilement of the race . . . Imbecility will breed imbecility and where there is a trace of feeble-mindedness in a family it is sure, sooner or later, to reappear, the defective 'germ plasma' producing an abnormal" (Barr, 1915).[141]

"We must come to recognize feeble-mindedness, idiocy, imbecility, and insanity as largely communicable conditions or diseases, just as the ordinary physician recognizes smallpox, diphtheria, etc., as communicable" (Sprattling, 1901).[142]

When Goddard (1912)[143] was asked whether feeble-mindedness could not be the result of poverty and malnutrition, he said: "There is not the slightest evidence that malnutrition, or any environmental condition can produce feeble-mindedness."

A logical conclusion of the foregoing line of reasoning was that aside from euthanasia, only preventing the retarded from reproducing could reduce their number. Barr wrote an article entitled *The Prevention of Mental Defect, The Duty of the Hour,* which began: "That the prevention of the transmission of mental defect is the paramount duty of the hour, is a truism not to be questioned." The article contained the following memorable lines: ". . . One cannot fail to recognize the necessity for the enforcement of measures which experience has demonstrated as absolutely needful steps toward prevention, viz: The separation, sequestration and asexualization of degenerates . . ." (1915).[144]

Other writers added: "The successful control of amentia is the most imperative of public duties," ". . . Conserve the mental virility and moral integrity of the race" (Schlapp, 1915).[145] "The present generation is the trustee for the inherent quality as well as for the material welfare of future generations" (Fernald, 1915).[146] ". . . We absolutely cannot afford to wait" (Knight, 1898).[147]

Much study was given to the means of prevention. Private and public study and action groups proliferated. In 1903, there existed a Committee on Colonies for and Segregation of Defectives of the National Conference on Charities and Correction. By 1915, seven states had public commissions (Schlapp, 1915)[148] much like our governors' committees today. Several other states had unofficial commissions, and several cities had commissions much like the recent mayors' committees. The national Committee on Provision for the Feeble-Minded had its headquarters in Philadelphia in 1916 and its purpose was "to disseminate knowledge concerning the extent and menace of feeble-mindedness and to suggest and initiate methods for its control and ultimate eradication from the American people" (as quoted by Johnstone, 1916).[149] This committee was credited with being instrumental in giving 1,100 lectures to about 250,000 people, establishing institutions in nine states that had none, increasing the number of existing institutions in five states, and extending the sizes of existing institutions in four states (Davies, 1930).[150]

One of the more influential study groups was the Eugenics Section of the American (Cattle) Breeders Association, which, curiously, later became the American Eugenics Society and the sponsor of the respected contemporary journal *Eugenics Quarterly*. This group issued a well-known report (summarized by Van Wagenen, 1914)[151] that considered 10 possible measures, judging only 2 to be practical: Sterilization, and segregation of those retarded persons capable of reproduction. In general, there was a ". . . keen interest in everything pertaining to the mentally deficient both in Europe and in this country. The realization of the vast extent of mental defect, the inexorable requirements of the modern graded school systems with the study of the resulting retardation, the popular application of the Binet and other psychological tests, are some of the causes of this interest. Mental deficiency has become a subject of vital and pressing significance to physicians, psychologists, teachers, court officials, social workers, and legislators. The subject is being studied from medical, biological, pedagogical, psychological, sociological, economic, and eugenic points of view. The field of mental defect has been so broadened and extended as to include all the professional disciplines" (1913, cited by De Prospo, 1966).[152]

Belief in the genetic causation of retardation had some convenient aspects. By proposing that most social problems would be solved if the poorer members of society would stop having children, people could feel freed from a sense of responsibility for bad social conditions. Furthermore, they were relieved from worrying about the effects of slum conditions upon children, if they could believe that many such children were genetically inferior to begin with. It is probably no coincidence that the indictment period overlapped with periods during which Social Darwinism and laissez-faire socio-economic policies were prominent.

Failure of Preventive Marriage Laws

In order to understand how institutions for retarded Americans developed as they did, we must understand the failure of alternative provisions.

During the indictment period, the only hope seen was in the prevention of procreation of individuals likely to produce retarded persons. Three methods suggested themselves: forbidding the mating of retarded persons by law; preventing procreation, of those retarded persons who might mate, by sterilization; and preventing both mating and procreation, by means of segregation.

Outlawing of procreation was attempted early in the alarmist period. In about 1895, House Bill 681, containing the following provision, was passed in Connecticut: "Every man who shall carnally know any female under the age of 45 who is epileptic, imbecile, feeble-minded, or a pauper, shall be imprisoned in the State prison not less than 3 years. Every man who is epileptic who shall carnally know any female under the age of 45 years, and every female under the age of 45 years who shall consent to be carnally known by any man who is epileptic, imbecile, or feeble-minded, shall be imprisoned in the State prison not less than 3 years" (Beedy, 1895).[153] Similar bills were soon passed, and some of these bills were still on the books in 1965.

A national marriage law to prohibit marriage to the feeble-minded and insane was proposed as early as 1897 by Wells[154] and was widely supported. In 1899, what is now the American Association on Mental Deficiency appointed a committee to explore cooperation with the National Conference on Charities and Correction, the Prison Congress, the Medico-Psychological Society, and other bodies that might be interested in supporting restrictive marriage laws *J. Psycho-Asthenics*, 1899).[155]

The ineffectiveness of marriage laws was soon recognized: "Restrictive marriage laws are no doubt advisable, but . . . unavailing because the unfit reproduce their kind regardless of marriage laws" (Murdoch, 1913).[156] Alas, sex, even less than alcohol later on, was not easily outlawed. However, sterilization suggested itself as a reasonable alternative.

Failure of Preventive Sterilization

Sterilization, or as it was also called, asexualization and unsexing, was apparently first advocated to a significant degree in the mid-1890s. Like virtually all administrative measures which the nondeviant people design to manage deviant ones, sterilization was often rationalized as being to the retarded person's advantage. Barr (1902)[157] called for ". . . invoking the aid of surgical interference to secure . . . greater liberty, therefore, greater happiness to the individual . . ." This was echoed by Perry (1903):[158] "It would now be well to prepare our several states to call to our assistance the surgeon's knife to prevent the entailing of this curse upon innocent numbers of yet unborn children." Barr asked: "Knowing the certain transmission of such taint, how can one fail to appreciate the advantage of prevention over penalty, or to recognize as the most beneficent instrument of the law the surgeon's knife preventing increase. And why not? We guard against all epidemics, are quick to quarantine small-pox, and we exclude the Chinese; but we take no steps to eliminate this evil from the body social" (1902).[159]

It was soon recognized that sterilization, in order to reduce the number of the retarded to an appreciable extent, had to be compulsory, and such laws were passed throughout the nation and generally upheld by the courts.[160,161,162,163,164,165,166] However, it was also found that sterilization laws were only slightly more enforceable than mating laws; that not all retarded persons were reached by the laws; and that sterilization would not prevent as many cases of retardation as had been thought:

"Compulsory surgical sterilization of all defectives is proposed as a radical method for preventing the hereditary transmission of feeble-mindedness. At least six states have passed laws authorizing or requiring this operation. In no state, however, has this remedy been applied on a large scale. There are many objections to this plan. The friends of the patients are not willing to have the operation performed. The normal 'carriers' of defect would not be affected. The presence of these sterile people in the community, with unimpaired sexual desire and capacity would be direct encouragement of vice and a prolific source of veneral disease. Sterilization would not be a safe and effective substitute for permanent segregation and control" (Fernald, 1912).[167]

"The sterilization of feeble-minded is now universally acknowledged to be impracticable, principally because the hereditary influence in this field has not been quantitatively determined, because the operation is dangerous, the idea more or less revolting and, possibly, because it is not in consonance with the religious thought of a certain portion of the community. Sterilization, therefore, need not be further discussed at this time" (Cornell, 1915).[168]

Failure of Preventive Segregation

Once mating laws, sterilization, and other measures had been recognized as ineffective or unacceptable in preventing the spread of the "retardation menace," only segregation (Fernald in 1915[169] called it "strict sexual quarantine") remained, and it was advanced with utmost vigor by the workers in the field. First, of course, it had to be rationalized to be, at least in part, for the welfare of the retarded person. An editorial in the *Journal of Psycho-Asthenics* in 1899[170] asked: "Of what is a high-grade imbecile deprived on entering a well-conducted institution?" and concluded he would only be deprived of deprivation. Winspear (1895)[171] reasoned as follows:

"A moment's thought, and the fact is plain that unprotected feeble-minded women of full physical development are in constant danger themselves, and are always a menace to society—a twofold reason why custodial care for this class should be the paramount idea in the State's provision for the feeble-minded. Thus their proper care and protection is a twice blessed charity, in that it blesses the recipient of the State's bounties and blesses society by the removing of a great evil therefrom."

More direct arguments included the following: "Shall we turn these irresponsibles loose to undo the work of the past and redouble that of the future? Surely history would not write our names among the wise" (Barr, 1899).[172] ". . . I think we need to write it very large, in characters that he who runs may read, to convince the world that by permanent separation only is the imbecile to be safe-guarded from certain deterioration and society from depredation, contamination and increase of a pernicious element" (Barr, 1902).[173] "But all of them whether able of productive labor or wholly helpless, or of any grade between these extremes, ought to be permanent wards of the state so long as they shall live" (Johnson, 1901).[174]

In 1905, retarded adult males were characterized in the Maine Senate as "town loafers and incapables," "petty thieves," "incendiaries," sources of "unspeakable debauchery" which "pollute the whole life of young boys" and who "have illegitimate children every one of whom is predestined to be defective mentally, criminal or an outcast of some sort." Such individuals were to be placed in an institution, and the institution, in turn, was to be placed in an isolated spot. These measures were to save the communities of the State of Maine from "terrible menace" and "economic burdens" of the feeble-minded whose "uncontrolled life and movements threatened great harm to society" (quoted by Levinson, 1960).[175]

"The only just and humane and civilized way of stopping the transmission of defectiveness is by segregation" (Johnson, 1908).[176] "Every effort must be made to get these defectives out of society . . . the degeneracy must cease here" (Johnstone, 1904).[177]

Consistent with the proposal advanced earlier that retardation should be treated as a communicable disease, Murdoch in 1909[178] gave a paper entitled "Quarantine Mental Defectives." Johnstone (1904)[179] called for a ". . . quarantine of this social disease . . ."

"On the most important proposition of all—who gets born—last year Governor Foss vetoed an increased appropriation for our second school for the feeble-minded. This year, however, provision was made for two new cottages, which will hold 200 inmates, and cut off by, perhaps, half that number a source of supply of the unhappy and unfit among future generations. The righteous have sworn the segregation of all the feeble-minded for 1925" (*Reports from States*, 1912).[180]

Not only were the retarded to be segregated from society, but even within institutions, men and women were strictly segregated, almost to a paranoid and bizarre degree: "The institution that places . . . boys and girls anywhere near each other . . . will never do its part in the work of preventing feeble-mindedness in the community . . . The institution superintendent who allows feeble-minded boys and feeble-minded girls to work together even in the garden, is running the risk of a second generation of illegitimate feeble-minded children" (Cornell, 1915).[181]

If it was difficult to keep men and women apart within an institution, then separate institutions for the sexes might be the answer, and a number of such institutions were maintained or built: "Custodial care for feeble-minded women of full physical development, in distinctly separate institutions, which was at first considered by many a doubtful experiment, has proved a grand success, and should be followed by every other state in this country" (Winspear, 1895).[182]

The extreme in segregation was advocated by Barr who proposed the establishment of one or more national institutions or reservations (Barr, 1897,[183] 1899,[184] 1902;[185] Dunlap, 1889)[186] similar to the management of another large deviant group in America, the Indians: "The National government has provided for the Mute, the Negro, and the Indian—then, why not for this branch of population increasing as rapidly as they, and becoming yearly more inimical to national prosperity. A reservation set apart, affording facilities for agricultural pursuits as well as all the varied industries of a town, would provide an outlet for the surplus population of our institutions, to find there a home with definite life aims constantly realized. Such a colony, under such restrictions and protective care as our experience has proven is essential, a congregate number of institutions, so to speak . . ." (Barr, 1897).[187] "Protected from the world and the world from them, these children of the nation, instead of as now, its standing peril, would be a constant object lesson, at once a reproof and a warning to guide us to that 'statelier Eden of simpler manners, purer laws' which the twentieth century shall usher in" (Barr, 1899).[188]

Workers in the field were, at times, rather unrealistic. They exhorted the public to marry on a eugenic rather than emotional basis, and to forego marriage altogether if presumably inheritable detrimental traits were observed in their families. Similarly, some workers appealed to parents to institutionalize their children voluntarily: "Greater efforts must be made to have the great public know of the defectives, so that we shall not be accused of having axes to grind when we ask for more provision for them. Institution men must encourage visits, give out information and indeed, conduct a campaign of education, so that in the first place the willingness of parents to send their children shall be changed to eagerness, and then will follow the demands of public opinion and the concessions of legislatures" (Johnstone, 1906).[189]

At the end of the founding period, legislatures had been asked to permit residents to stay. As late as 1902, discharges from institutions were easy and informal (Wilmarth, 1902).[190] However, the tone changed during the alarmist period, and increasingly, laws and rules mandated legal and quasi-permanent commitments rather than voluntary and temporary ones.

Since segregation was for the protection of society, it was only logical that commitments should be compulsory: "Segregation does not mean the opening of a boarding home by the state in which parents may place their feeble-minded children, have them trained by much labor, to the point where they become dangerous to the community if allowed at liberty, and then remove them and turn them loose" (Cornell, 1915).[191] Johnstone (1908a)[192] recommended that admission of "degenerates" require a trial and an indeterminate sentence. Release would also be only by trial, although little need for such trials was seen: "The only possible reason we can urge for their being set free is a sentimental one . . ."

Apparently, Illinois was the first state to require court commitments, as of 1915 (Harley, 1917),[193] to the exclusion of all other types of admission. Laws of this nature were criticized, not on legalistic or humanistic grounds, but because they might discourage parents from admitting their children (e.g., Carson, 1906).[194]

We are left with the distinct impression that sensing the impending failure to segregate all the retarded, workers in the field vented their frustration by striving to increase the degree of segregation of the retarded individuals already in their custody. Also, the fact that retarded residents had been released into the community both before and after the indictment period would appear to indicate that the decline of successful rehabilitations early during the indictment period was an artifact of institutional policy. In other words, residents were not released by the institution personnel because the personnel did not believe that residents could or should succeed. For instance, until 1967, retarded persons in Nebraska gained entrance to the state institution only by court commitment; once committed, they could, until 1963, only be released if they were sterilized or otherwise incapable of reproduction. Even in 1968 the law still required that release be preceded by a time-consuming expensive review by a sterilization board.

The professionals in the field were thoroughly convinced that the survival of society required that the largest number of retarded persons be institutionalized as fast as possible. Here, however, they encountered limitations in funding institutions, and the public and legislatures were not channelling additional funds as fast as the professionals thought they should. "The public, while liberal in all its charities, demands that the funds so appropriated should be wisely and economically expended, and that the cost should be kept as low as possible, consistent with the best methods of carrying on the work" (Wilmarth, 1902).[195] "Our taxpayers are already groaning under the burden of caring for the actual imbecile and the epileptic" (Fernald, 1908).[196]

First, there was an attempt to convince the public that financial support of institutions would save money in the long run: "This special care is now recognized as not only charitable, but economical and conservative. Each hundred dollars invested now saves a thousand in the next generation" (Fernald, 1893).[197]

"As a simple business proposition no state can make a better investment, or one actually paying larger dividends, than to insure that the feeble-minded women of child-bearing age are prevented from bringing defective paupers into the world to go on reproducing themselves in geometrical ratio. The direct money saving from this result alone in a few generations would represent a sum equal to the cost of maintenance of the entire feeble-minded population of the state. The much quoted history of the Jukes family showed that in 75 years the community paid over one and one-quarter millions of dollars for caring for the paupers and prosecuting the criminals who were the direct descendants of 2 feeble-minded sisters" (Fernald, 1904).[198]

"If my estimate is within bounds, the entire money cost of removing this dreadful stain from our nation would be, after an expenditure by each state of an average amount of less than half a million for lands and building, a maintenance fund of about 10 cents per annum for each of the inhabitants of the United States.

"How foolish is the action of the public in saving such a small amount at the spigot and wasting so profusely at the bung! Ought not this question be made a burning one? Ought not every one convinced of these facts to cry aloud, and spare not, until the legislature of every state shall have the facts burned into their hearts and consciences, as they are now into ours?

"Unfortunately, it is the superintendents of state institutions who are usually compelled to propose the extension of their work. And then they are accused of extravagance, of a desire to glorify themselves at the expense of the taxpayer. The truth is that they are the ones who feel most keenly the needs that they assert; and, if they do not speak, all will be silent" (Johnson, 1896).[199] "The cost of segregation will be large, but not so large as the present cost of caring for these same persons, to say nothing of their progeny in future generations" (Fernald, 1915).[200]

But some years earlier, in one of the first public statements of indictment, Walk (1890)[201] had predicted correctly: "If you are going to shut up all the idiotic and feeble-minded where they can do no harm, you must do it in a cheap way . . . If it cannot be done at a cheap rate, you can never get money to do it."

The professionals were caught between their convictions about the absolute necessity to segregate the largest numbers of retarded people, and the limitations of legislative appropriations. In desperation, they developed three interrelated plans: (1) by reducing per capita costs, more people could be admitted on a given budget; (2) by increasing the population of institutions, per capita costs would come down; (3) by having higher-functioning residents work the land and take care of lower-functioning residents, costs would also be reduced. If these proposals were implemented, perhaps costs could be so reduced that eventually all retarded people might be enfolded in the institution. This thinking intensified the trend toward economy discussed earlier as a concomitant of the pity period.

An argument that became very popular was that since most community breadwinners must support three or more persons, a retarded resident who was one-third as productive as a community worker would be self-supporting. At least for a while, everyone apparently believed that self-sufficiency and complete segregation of the retarded was to be achieved through the work potential of the residents.

"The only hope that I can see of the state taking complete care and responsibility of all idiots and imbeciles is that all those who have been trained, those of the higher grade who are susceptible to training, who have been trained to the highest degree possible for them, shall be so usefully employed that they may be practically self-supporting. We need a great deal of low grade labor, and a great deal of labor can be performed by laborers of low degree of intelligence. In the care of the lowest custodial grade of imbeciles, in the care of epileptics of low grade, there is a great deal of labor available among our trained imbeciles; and they can do no better work than to exercise such care in an institution" (Johnson, 1902).[202]

Beginning about 1880, so-called farm colonies had come into vogue. In essence, they were institutions that specialized in making the less retarded individuals as self-supporting as possible by having them farm large tracts of land. Knight (1891),[203] Fernald (1902),[204] Mastin (1916a,[205] 1916b),[206] and Bernstein (1920)[207] presented key models of such facilities. The belief developed that with enough land, an institution could actually become self-supporting. The rule of thumb that appeared to materialize out of nowhere (e.g., Osborne, 1891)[208] was: One acre per resident. "Having decided upon the number of inmates, at least one acre of land for each inmate should be purchased" (Fish, 1892).[209] "It has been conceded for years that each institution should be provided with at least one acre per inmate; and, as we grow in years, it is thought by some that even more than this is needed" (Powell, 1897).[210] "The colony estate should be large, fully an acre to each individual. It is far better to have a little too much land than too little. We have at Sonyea 1895 acres, on which it is proposed ultimately to place 1800 people" (Sprattling, 1903).[211] "The site for an institution should comprise one acre of land for every pupil when the institution has reached its maximum" (Wallace, 1924).[212]

With such a rule of thumb, institutions soon became monstrous in extent: "The colony farm for the adult feeble-minded of Massachusetts is one of the largest of its kind in the world, covering several square miles of land" (Johnson, 1903).[213] "The Craig Colony estate (in New York), three miles long and a mile and half wide . . . " (Sprattling, 1903).[214] Powell (1897)[215] provided detailed information on U.S. institutions, including number of residents and land holdings. If one computes the average acreage per resident, one arrives at a figure of 1.01. By 1915, Bureau of the Census (1919) data indicate that average per resident acreage had risen to 2.47 or 2.99, depending on how the average is computed. By 1922, the heyday (hayday?) of farm colonies seemed to be past, as average acreage was down to 1.31, and by 1933, it had fallen further to .62 (Bureau of the Census, 1926, 1935).

Doren had been superintendent in Ohio for many years, and in 1884 he reported that 24 to 30 percent of residents "become capable of self-support" (Kerlin, 1884).[216] In the mid-1880s, Doren made a fateful boast: "The superintendent of the Ohio institution has made a proposition to the legislature of that state like this: Give me the land and allow me to gather the idiotic and imbecile population now under public care together, and I agree that the institution shall be made self-sustaining, and I will pay back to the state the price of the land" (Byers, 1890).[217] As widely quoted and repeated, (e.g., Kerlin, 1886;[218] Knight, 1891,[219] 1892;[220] Fernald, 1893;[221] Follett, 1895;[222] Bicknell, 1896;[223] Byers, 1916),[224] Doren was said to have stated that 1,000 acres would suffice to carry out his claim.

"I am quite sure that with sufficient farm land, and in connection with our present institution, the adult able-bodied imbeciles of both sexes could be kept in our state at a weekly cost of not more than $1 per capita in addition to what the farm would produce" (Johnson, 1896).[225] By 1902, Johnson[226] stated that the average annual maintenance cost in an Indiana farm colony was actually down to $32, which must have referred to a very select subgroup, as overall maintenance costs in Indiana were about $136 in 1902.

Residents were worked to the limit of their capacity, and, it appears, sometimes even beyond: "They should be under such conditions that many of them shall not cost the tax-payer anything . . . the state must . . . say to them 'We will take care of you: you shall be happy and well cared for and clean and useful; but you shall labor and earn your bread in the sweat of your face according to the divine command.' That is what ought to be done with the whole class of degenerates, just so far as it is possible to do it" (Johnson, 1901).[227] Mastin (1916)[228] declared that what was ". . . heart-breaking and unprofitable work for normal persons . . ." would be ". . .'particularly fitted' . . ." and ". . . agreeable, if not joyful occupation . . ." for the retarded persons. ". . . You cannot work those boys too hard. If they work them as hard as they can they will not practice the vices. . . . Let them go out and work just as hard as they will work. That is what they have to do for me when they work on the farm. They work so that when they come in at night they go to bed and sleep. Then they get up the next morning and go to work again, and I am very sure that the farmers who are working them the hardest are keeping them the best in line of good behavior" (Bernstein, in Fernald, 1912).[229,230,231,232,233,234,235]

Residents might not only be worked like animals, it seemed, but also received about as much (or even less) medical care: Mastin (1916a,[236] 1916b)[237] and Swan (1908)[238] boasted that medical expenses for over a year in one of the Massachusetts farm colonies was a total of less than one dollar for all 50 resident males combined. This stands quite in contrast to Fernald's earlier description of a farm colony, prior to the cost squeeze: "They have their baseball nines and their football teams. They go coasting and skating in the winter and swimming in the brook in the summer. What more can a boy want?" (1902).[239]

There was much self-delusion and falsification of facts regarding maintenance costs, and I found it difficult to distinguish between claims as to: how many residents were discharged as self-supporting; how many were considered potentially self-supporting in the community (estimates varied between 10 and 50 percent); what the maintenance costs were and what the maintenance costs might have been.

"Dr. Walter E. Fernald, of Massachusetts, in speaking on this subject, says: 'Not over 10 or 15 percent of our inmates can be made self-supporting, in the sense of going out into the community and securing and retaining a situation, and prudently spending their earnings. With all our training we cannot give our pupils that indispensable something known as good, plain common sense' " (Carson, 1898).[240] The superintendent of Lapeer, Michigan, claimed: "Twenty-five percent of our inmates would be self-supporting if the work were put into their hands to do" (Polglase, 1900).[241] "Mr. Alexander Johnson says that in his institution 50 percent of his inmates are self-supporting" (Fox, 1900).[242]

"The proportion of the feeble-minded who may be made to earn their own living, under control, is variously estimated. The superintendents of at least two of the large training schools, both men of practical common sense, place the estimate as high as 50 percent of the whole number admitted.

It is instructive to notice that estimates of this kind tend to become larger, especially as made by the managers of institutions which have a large acreage of farming and fruit-growing lands" (Johnson, 1898).[243]

"The cost of maintenance for mixed classes of patients in colonies after the population reaches 600 to 700 will be less than for the insane; while colonies for selected cases only should not require more than $75.00 to $80.00 a patient year, and under ideal conditions even less" (Sprattling, 1903).[244]

"Build them up as high as you can, keep them where they are safe and will be industrious and half of them, perhaps more than that, may be entirely self-supporting and no burden upon the tax-payer at all" (Johnson, 1905).[245] While records show that maintenance costs in Pennsylvania were about $175 a year, superintendent was quoted as follows: "Dr. Kerlin tells me that, when they had 300 inmates, it cost them $20,000 for expenses. Now with 700 inmates, it does not cost any more.

What does that mean? It means that the feeble-minded themselves are doing the work and helping to solve their own problems" (Barrows, 1888).[246] Even though Kerlin was probably misquoted, it is significant that prominent workers in the field were ready to believe that costs were down to $29 per year.

Fernald stretched the truth a bit in the following statement: "The average running expenses of these institutions have been gradually and largely reduced by this utilization of the industrial abilities of the training inmates. At the Pennsylvania institutions the per capita cost of all the inmates has been reduced from $300 to a little over $100 per annum . . ." (1893).[247] The records showed Pennsylvania costs to vary from $152 to $175 between 1889 and 1894. Johnson (1900)[248] and Bernstein (1918b)[249] gave boastful papers on "self-sustaining" residents even as the maintenance costs at Bernstein's Institution (Rome, N.Y.) were $150 a year.

A breakdown of the 1928 average maintenance costs of 24 farm colonies for males at Rome State School showed a range of $186–508, with a mean of $260 and a median of $232 (Davies, 1930).[250]

While resident labor, and development of farm colonies did not make the institutions self-sufficient, costs were, indeed, reduced, held constant, or held down to an astonishing degree. Superintendents vied with each other in reducing cost, and aside from farming, another way to economize was to develop institutional architecture that was "plain but substantial": "The buildings themselves should be exceedingly plain and simple. What intrinsic reason is there for building more expensive structures than middle-class people build for their own dwellings in the same community?" (Fernald, 1902).[251] "Plain, substantial buildings, with modern sanitary toilet facilities, and of architectural beauty, but no filigrees, are what we need" (Johnstone, 1908).[252] ". . . Permanence in construction with low maintenance cost . . ." (Kirkbride, 1916).[253] "The institution that we provide for the feeble-minded should be constructed and maintained at a moderate cost. There has been a disposition to build marble palaces for the most degenerate members of the community . . ." (Cornell, 1915).[254]

Stripping the residents' environment of amenities and comforts to cut costs was accompanied by tortuous rationalizations: "As a rule, mental defectives are descended from the poorer classes, and for generations their people have lived in homes having few conveniences. To expect them to be content in a great city institution with its up-to-date furnishings and equipment, and its strict routine, is unreasonable. They find little comfort in steam heat and polished floors; and the glare of electric lights too often adds to their restlessness. It is useless to hope that they will ever be happy as it is possible for them to be if we do not gratify their love for open spaces or provide for them the opportunity to live the simple out-of-door life under circumstances which will enable them not only to keep busy but to enjoy the fruits of their labor" (Mastin, 1916a).[255]

A statement uncomfortably close to suggesting human warehousing was attributed to Fernald by Kirkbride (1916).[256] "It is obvious that if large numbers of the feeble-minded are to be cared for, the cost of housing them must be reduced to a point where it cannot be criticized by the business man and the tax-payer." "The ornamental or decorative features of the old-time institution will have to go, if this is to be accomplished." "We have only begun to utilize the beautiful, well-proportioned commercial type of buildings, such as the General Electric Co., the Bridgeport Arms Co., etc. are building."

In the early days, costs at Elwyn in Pennsylvania had been $350; by about 1890, they were down to about $175 (Kerlin, 1890),[257] and to $152 in 1893. Wilbur[258] estimated that average maintenance costs were about $200 in 1888. Powell (1897)[259] thought that cost could be reduced to about $150 or even $125. Almost in desperation, Cornell (1915)[260] exclaimed: "Until we get the per capita cost of the high grade feeble-minded down less than $100 per year there will be objection to their segregation on the ground of expense."

Although attempts to become self-supporting failed, the relative true expenditures hit a low during the indictment period, not to be equalled even during the depth of the depression. As costs went down (at least in relation to the value of the dollar), admissions went up. Successively larger institutions were rationalized as being of ideal size, and as size grew, the rationalizers moved on from one rationale to the next. According to Fish (1892):[261] "One thousand inmates should, in my opinion, be the maximum number under one management . . ."

Knowing what was to come, we shudder as a small voice of caution is brushed aside: "Mr. Garret has referred to the fact that, in the establishment of an institution for 1,000 of the feeble-minded, the identity of the individual child may be lost sight of. I think there is possibly some ground for that fear; but in our institution, which is planned to care for a thousand eventually, we do not find any lack of the same personal care and interest on the part of caretakers and attendants. Their enthusiasm and interest are just as great as in the beginning of the work. I do not anticipate any evil results in extension of the work on the line suggested" (Fish, 1892).[262]

H. M. Greene (1884)[263] and Wilmarth (1900)[264] suggested that institutions not exceed 1,000. Murdoch (1909)[265] expressed the hope that his institution would remain at 1,340, but by 1913 he had capitulated, calling for 2,000–3,000. R. A. Greene (1927)[266] called an institution for 1,000–1,500 "ideal." Sprattling (1903)[267] was planning an institution for 1,800. Hart (1896)[268] of Minnesota said: "Our buildings are excellent; but they sadly need enlargement. We could have, I think, 2,000. The demand is convincing and unanswerable." "I do not believe that the size of an institution should be so limited. It seems to me that 2,000 or 3,000 can be cared for in one institution when the possibilities of grading and grouping are so great. Why should we not have towns of them? If the superintendent is an organizer, it is a benefit to the state to take care of 3,000 in one institution. I would not put any limit to the number that a man can properly handle" (Smith, 1913).[269]

Finally, the cork was pulled altogether: Polk (Pennsylvania), which had been build to relieve crowding at Elwyn, and which had had 1,200 residents in 1906 (Murdoch, 1906),[270] had grown to 2,300 residents, 84 percent overcrowding, and a waiting list of 500 by 1928 (Watkins, 1928);[271] Columbus (Ohio) had 2,430, with construction underway for 240 more, and funds appropriated for yet another 700.

Superintendent Emerich threw up his hands; much like Fernald (1893),[272] he said, in his presidential address to what is now the American Association on Mental Deficiency: "It seems easier to get the legislature to appropriate funds for more buildings, for the institutions we already have, then it does to get new institutions, but as the institution at Columbus is now so large that the Superintendent cannot keep in touch with the inmates, it might just as well have a population of 10,000 as 3,000" (Emerich, 1917b;[273] see also, Emerich, 1917a).[274]

A peculiar but commonly repeated twist of logic in support of enlargement was advanced as early as 1895: "Each year the number committed to our care has been a considerable increase over that of the preceding; and we have now reached a population at which our extended accommodations are exhausted, with numerous applicants knocking at our doors for admission. Provisions to meet this demand are already near completion. This numerical statement is a most gratifying proof of the good work of the institution, and positive evidence of the full confidence of all public-minded, charitable citizens." (Winspear, 1895;[275] Davies, 1959).[276]

The menace image of the retarded, and the perceived necessity to farm large tracts of land for large groups of residents, combined to result in the locating or relocating of most institutions away from population centers and in rural areas where farm land could be had inexpensively. This exacerbated the trend toward isolation begun during the pity period.

In 1913, J. M. Murdoch[277] called for institutions of 2,000–3,000 located ". . . far from any large city and rather isolated . . . " and on 3,000–4,000 acres of land. By 1930,[278] isolation had become so accepted and real that he reversed himself slightly, advocating, in all seriousness, that institutions ". . . should not be too isolated, and should be near enough to a village where employees may do their shopping, find social interest, and entertainment . . ."

For a long time, Johnstone (brother-in-law of A. Johnson) and Kirkbride were the only ones to raise a voice in partial opposition to the prevailing thinking. For several years, the myth was maintained that farm colonies would eventually attain self-sufficiency, and considerable discrepancies are apparent between euphoric public claims and actual cost figures. This situation led Johnstone to observe: "The farm colony idea, with a reasonable number of paid employees and a large extent of farm land, has made many institutions much nearer self-support, but still the per capita cost is over $100 per annum. Many of us have hitched our wagons to this star, but the millenium cometh not yet" (Johnstone, 1906).[279] He also objected to the continuing enlargement of institutions (e.g., 1908,[280] 1913)[281] and argued for some semblance of humanizing treatment of the retarded generally: "I have not gotten beyond the 500 or 600 mark as yet. From an economical standpoint, I believe about 750 would be the most desirable size. I have argued against a large number being placed in one institution for that reason. If the institution is not very large, we get good classes. When we put men in one institution, women in another, and children in another, are we not taking away entirely the family idea?" (1913).[282]

Johnstone can be seen as "least extreme," but as far as opposition to the principle of segregation was concerned, there was absolutely none from the professional ranks: "We must beware of assuming universal consent because no serious note of opposition has been heard" (Johnson, 1903).[283] Personally, I found it both instructive and depressing that between about 1890 and 1918, not a single speaker or writer opposed the prevailing views of retarded people as a sinister menace. What will future reviewers say of our own epoch?

Failure to Support Community Alternatives to Segregation

The workers in the field painted themselves into a corner by advocating a practically unfeasible, scientifically invalid, and sociopolitically unacceptable policy of segregation while systematically rejecting alternative provisions such as education and family support.

During the alarmist period, education was no longer seen as effective in diminishing the degree of a person's retardation, and was not believed to prevent a retarded person's depravity: "When the state has taken the imbecile, and by training has brought out the best there is in him, when it has corrected his faults, so far as education can do it, when it has possibly taught him to read and write, to be more engaging in his manners and more attractive in appearance and bearing, and then has discharged him with his inherent defects in no way removed, to marry and perpetuate his kind, has it really done a commendable deed?" (Wilmarth, 1902).[284]

Thus, education came to be viewed as worthless. Rogers (1898),[285] superintendent of Faribault (Minn.), questioned: "Does the Education of the Feeble-minded Pay?," and Johnson (1899)[286] stated: "We made a mistake in keeping many children in school too long and taking them farther than they will have any need for." Bernstein (1913)[287] observed: "The patients who give us the most trouble are the ones who have been taught to read and write. They are always looking for an opportunity to send out a letter or note secretly, and give us trouble in other ways as well. If they could not write, much of the disturbance would be eliminated."

Even special education in the community, far from being seen primarily as a constructive and viable alternative, was seized upon as a means of identifying the retarded for subsequent institutionalization: "If . . . the special schools were so conducted as to constitute clearinghouses to separate the inherently feeble-minded from those whose mental growth is retarded by circumstances temporary in character, they would serve a useful purpose; but if they are attempting the impossible, the education of the inherently feeble-minded to equip them to battle single-handed in the struggle for existence and thus prevent their entrance into institutions during their early years, they are harmful. It is our duty to point out the limitation of usefulness for such schools" (Murdoch, 1903;[288] similarly, 1909; [289] Fitts, 1915;[290] and Schlapp, 1915).[291] "The modern public school class for defective children ensures diagnosis and treatment at an early age, helps to inform the parents as to the dangers of mental defect, and admirably serves as a clearinghouse for permanent segregation, when necessary before adult life is reached. These classes should be established in every city and large town" (Fernald, 1915).[292]

Another community alternative—today thought most progressive—the granting of a subsidy or "pension" to needy families with retarded persons in the household, was viciously attacked. Kentucky had had such a law since 1793 (Estabrook, 1928;[293] Fernald, 1893),[294] but superintendent Stewart from Kentucky (1894)[295] confessed that he was " . . . ashamed to tell you of our idiot law," and said that he had tried for 16 years to have the law repealed. He likened this law to the scalp law for foxes under which every fox scalp was rewarded with a $2.50 bounty unitl people took to raising foxes. "Now there is a premium offered for idiots." "The system is heinous" *(Reports from States*, 1890).[296] Dunlap (1889)[297] also expressed disapproval of the pension law, and Estabrook (1928)[298] suggested that it be repealed and the money used to enlarge the institution instead!

Finally, even the newly developing psychological community clinics were interpreted as agencies of the eugenic work (e.g., see *Journal of Psycho-Asthenics*, 1913)[299] rather than of community assistance.

The End of the Indictment

The peak of the indictment period was between about 1908 and 1912. By about 1920, workers in the field began to recognize from studies of the community adjustment of retarded persons, that they were not the menace as had been thought. Also, it was realized that the aims of segregation could not be achieved.

Taft[300] made one of the first major admissions of the failure of both sterilization and segregation in 1918: ". . . when by segregation we mean a fairly complete shutting off from society of all the feeble-minded, including the higher grade types, we ignore a profound aversion on the part of people in general to confinement for life for any human being, particularly when no offense has been committed commensurate with such punishment and when the individual to be segregated seems to the ordinary observer not to be very different from himself. This, combined with the feeling which relatives, particularly of the high grade feeble-minded have against segregation, makes any very complete program of this kind quite impossible for some time to come . . ."

As early as 1915, Fernald[301] had observed that "the courts are seldom willing to utilize even existing commitment laws without the consent of the parents, except in extreme cases." Perhaps the only justification for naming Howe's original institution for the Great Indicator himself is that Fernald, in the last years of his life, reversed his position, first in a celebrated speech in 1917. In 1919,[302] he said: "The average citizen is not yet convinced that he should be taxed to permanently support an individual who is capable of 30, 50 or 70 percent of normal economic efficiency, on the mere theory that he is more likely than a normal individual to become a social problem" (see also Fernald, 1924).[303]

"In practice it has been found very difficult to ensure life-long segregation of the average moron. The courts are as ready to release the defective as they are to commit him in the first place. However proper and desirable it may be in theory to ensure the life-long segregation of large numbers of the moron class, it is a fact that there is a deep-seated prejudice on the part of lawyers, judges, and legislators toward assuming in advance that every moron will necessarily and certainly misbehave to an extent that he should be deprived of his liberty. That such misgivings are well-founded is apparently shown by the studies made of discharged patients at Rome and Waverly. At Waverly, a careful study of the discharges for 25 years showed that a very small proportion of the discharged male morons had committed crimes, or had married or had become parents, or had failed to support themselves, or had become bad citizens." "We have begun to recognize the fact that there are good morons and bad morons, . . ." (1919).[304] After hearing Fernald in 1917, Murdoch (1917)[305] said: " . . . the pendulum . . . had gone too far and is coming back."

Taft (1918)[306] proposed a new alternative to the field: identification, supervision, and control of retarded persons in the community. This, it was widely felt, required that all retarded people be registered (Hastings, 1918),[307] and there was widespread agitation to accomplish this feat. Fernald had advocated such registries all his career (for partially different reasons), but now the idea found new support, although to no avail.

The 1930 White House Conference on Child Health and Protection proposed a three-stage program to attack the problem of retardation. Stage one was identification and registration; stage two was divided into training of some and segregation of others; and stage three involved supervision, or, as it was frequently referred to, "social control," of retarded persons in the community. Registration was the key to the entire program. A most prominent text of the time between the alarmist period and the new enlightenment of the 1950's was *Social Control of the Mentally Deficient* (Davies, 1923,[308] 1930).[309]

Today, of course, we know that most retarded adults make an adequate adjustment in the community, and that they are more likely to be the victims rather than the perpetrators of social injustice. It is also widely accepted that heredity is a relatively insignificant factor in the causation of retardation, as compared to maternal health and socio-cultural factors.

Momentum Without Rationales

We cannot understand the institution, as we know it today, with all its objectionable features, unless we realize whence it came. I propose that essentially, many of our institutions still operate in the spirit of 1925 when inexpensive segregation of a scarcely human retarded individual was seen as the only feasible alternative to combat a social menace. I am not proposing that this view is still held; I am proposing that most institutions function as if this view were still held.

From 1847 to about 1925, institutions had evolved dynamically as ideas, and innovations followed each other continuously. We can now judge the ideas faulty and the innovations as ineffective in achieving goals, but the force and dynamism of the institutional development cannot be denied.

By 1925, however, a curious situation had developed. Essentially, the large institution, built for the ages, remote from population and teaching centers, was bereft of rationales. The only major rationale left was relief for hard-pressed families of retarded individuals, and if this rationale had been taken seriously it would have called either for community services, and/or for specialized and dispersed residential units of a more humanizing character, and nearer to population centers. Furthermore, the institutions were so crowded that it might have taken a decade without any admissions at all to reduce residents to an appropriate number.

If the field had continued to evolve as logically as it had until about 1925, community and special residential services would have been developed, and institutions of the type we still have with us today would have withered away. However, community services did not develop fast enough, and this is probably one of the major reasons institutions did not change. Why these community services failed to develop is not simple to answer, but four reasons may be paramount:

- The professionals had indoctrinated the populace for about 30 years to the menace of retardation, and were to continue to assert the unchangeability of intelligence for another 30 years; thus, probably only a prolonged campaign of attitude modification (as finally developed in about 1950) could have secured community services.

- Partially because of the pessimism communicated by the workers in mental retardation, professionals became attracted to the discoveries and increasing treatment opportunities in the mental health field. A change in orientation of the National Conference on Charities and Correction reflected and/or contributed toward this trend. One of the organizers of this body in 1874 had been H. B. Wilbur, a pioneer in mental retardation. For almost a half century, the Conference was one of the major meeting grounds between professionals in mental retardation and other professionals and public officials. In 1917, the name was changed to the National Conference of Social Work; it became more of an association for one particular profession rather than a meeting ground and forum for many; and as papers on mental health and hygiene increased in frequency, papers on mental retardation began to diminish and eventually disappear.

- The depression stifled progress in the development of social services other than those considered essential to economic survival of the nation, and mental retardation services are generally given low priority even when times are good.

- World War II further diverted popular attention and concern. It is noteworthy that the "new look." in retardation began in about 1950 when there was prosperity and when war-related problems, such as demobilization, reintegration of veterans, and housing shortages, were finally being solved.

Any "institution" (in the sociological sense) that has much momentum but no viable rationale is likely to strive for self-perpetuation on the basis of its previous rationales and practices. And I believe this is what happened to our institutions (in the conventional sense). But 40 years of not thinking about our institutional models, and of model muddle (Wilkins, 1965),[310] is enough! Although these aspects no longer have viable rationales the institutional movement of today shares these aspects with the past.

- Large older institutions being further enlarged.

- New institutions designed for more than 600–1,000 residents.

- New institutions placed in inconvenient or remote locations.

- Perpetuation of the omnibus (rather than specialization) concept of institutional purpose.

- Uncritical and poorly rationalized intake practices; for instance, one need consider only the large number of young children with Down's syndrome from adequate families who are accepted, often in infancy or from birth.

- Continuation of dehumanization, despite the unprecedented move throughout the country toward increase in personal rights, equal protection under the law, distribution of affluence, better opportunities for the disadvantaged, etc. We have seen this concern expressed in civil rights laws, controversy over draft laws and the Vietnam war, definition of students' rights, reformulation of the rights of the accused, and the revision of the codes of ethics of many major professional societies. We are only beginning to see this concern extended to retarded persons.

III. The Realities of Institutional Accomplishments

If we compare the rationales for institution building with the realities of institution accomplishments, we can see that few of the hoped-for aims have even been approximated; that none of the major rationales advanced for institution building and institution running has held up; and that virtually every novel concept in institutional care was perverted eventually.

The schools became asylums, and small family residences became regimented institutions. Most of the retarded placed in these institutions were not made nondeviant; on the contrary, placement more often resulted in systematic "dehabilitation" (Sharman, 1966)[311] which accentuated deviancy. This was only to be expected, since any agency designed for the keeping of large numbers of deviant persons can ill afford to tolerate non-deviance in its midst.

The institution became not a paradise but a purgatory, not a garden of Eden but an agency of dehumanization; to this day, residents are subjected to physical and mental abuse, to neglect and inadequate care and services, to environmental deprivation, and to restriction of the most basic rights and dignities of a citizen.

In 1886, Kerlin[312] had a vision of what was to become the institution at Faribault, Minnesota: ". . . we turn most approvingly to Minnesota's noble offering for this charity. Located on the beautiful bluff on Straight River, Faribault, with a singularly attractive country adjacent, exciting the kindliest interest of an intelligent and warm-hearted community, and with every advantage of space, fertility of soil, and amplitude of water, we know of no institution in the United States so happily and wisely begun. In fact, like the noble state itself, this institution is only embarrassed by the richness of its opportunities."

Sonoma State Hospital in California was born in a vision: "The tract of land selected lies in the beautiful valley of Sonoma. It . . . embraces over 1,600 acres. It is watered by three living streams, two of which rise on the place and give us 100,000 gallons of water daily, at an elevation of 150 feet above the building site. There are over 50,000 fruit-trees on the place, besides acres of vines and hundreds of acres of pasturage. Two railroads pass through the land, and will give us stations on it. The climate is perfect, the situation picturesque, the location central; and, altogether, the trustees are jubilant, and feel that the millenium is at hand. There seems no reason why our Home should not be the equal of any institution in the land. We shall not be satisfied with any lesser glory". (Murdock, 1889).[313]

> "In mountain heights, past stream and plain,
> And by the redwoods forests' sweep.
> In this broad land a spot is found,
> Aye! call it ever hallowed ground."
> (Osborne, 1891).[314]

Could anyone believe that this hallowed garden of Eden became the Institution for 3,400 which was so criticized by a prominent visitor from abroad, (Bank-Mikkelsen), in *Children Limited*[315] and by a mother of a child there? (Anonymous, 1968).[316]

In 1901, an observer remarked that the retarded in a certain Midwestern institution were being herded like so many cattle (Clark, 1901).[317] Seventy-five years later, the residents were still being herded like cattle in the same institution. How many more years?

A 1787 visitor at Pennsylvania Hospital, the first U.S. public institution to receive the mentally afflicted for treatment, saw naked residents bedded in straw, in locked, underground, dungeon-like cells that had small windows for passing food, and he exclaimed in seeming self-satisfaction that ". . . every possible relief is afforded them in the power of man," rejoicing in ". . . the pleasing evidence of what humanity and benevolence can do . . ." (Deutsch, 1949).[318]

Deutsch also described a case cited by Dorothea Dix in 1847, in which a harmless deranged person was kept summer and winter in an open pen. He was fed hog slop and kept on straw which was changed every two weeks in summer, less often in winter. He was exposed to rain, heat, cold, and snow, and his feet had frozen off into shapeless stumps. The keepers of this wretch, however, saw themselves as offering kindly treatment.

Today, all of us see the inhumanity of such treatment, because our values have grown. But some of us do not see the present equivalents of the 18th and 19th century treatments, or of the keepers' responses. Are not denial of property rights, or human contacts and perceptual stimulation; restriction of movement and communication; denial of wages for work; compulsion to use nonprivate toilets; denial of the privilege to wear clothes; behavior control by medication rather than education or guidance; enforced idleness; and innumerable other practices common in our institutions, the equivalents of the inhumane practices of 1787 and 1847? Are not the rationalizations of these 1968 practices equivalent to the protestations advanced by the keepers of 1787 and 1847? How will the professionals and public of 2076 judge them?

Institutional segregation did not contribute much to prevention of retardation, and the devalued retarded person is still with us. Indeed, there is reason to believe that with the increasing complexity of life, the number of persons who will fail to meet societal demands will increase.

Institutionalization was not accomplished inexpensively, as had been claimed. The concentration of residents in large institutions has, in most cases, been more costly than provision of community services would have been. Work, first rationalized as constructive occupation, became exploitation as cost cutting became important and, again contrary to claim, only a modest number of the retarded residents became self-sufficient in the institution. Those who did become good workers began to replace institution employees and thus became too valuable to be released; the institution could not have functioned without unpaid captive labor. To save money, the large solid multipurpose (usually original) building of the institution was permitted to become an overcrowded dungeon; "cottages" conceived to replace them became large overcrowded buildings, sometimes housing 200 residents and their attendants (Bliss, 1913);[319] the "plain, substantial buildings" designed to reduce expenses became bare, vast mausoleums; and the colonies which were to relieve institutions of their crowdedness, bring about more humane living conditions, and reduce costs became large institutions in their own right.

The concentration of skilled expert staff never materialized, one of the main reasons being the isolation of institutions remote from centers of learning and population.

Employees, as much as residents in these isolated institutions, often become "institutionalized" (Cleland & Peck, 1967).[320]

To this day, staffing is a dilemma in both rural and urban locations. Recruiting for nonprofessional personnel is usually easier in rural locations unacceptable to many professionals. Professionals are easier to attract into urban locations, but there, nonprofessional turnover may run 50 percent a year, even with relatively good salaries (e.g., Jaslow, Kime & Green, 1966).[321] The very heterogeneity of residents, desired by many workers in the field, has presented a major problem in staffing because so many different skills and types of training are needed to serve a group with a tremendous variety of problems (Jaslow, Kime & Green, 1966).[322]

From the beginning, and ever since, the research potential of institutions has been exalted (e.g., Seguin, 1870;[323] Kerlin, 1885;[324] Sprattling, 1903;[325] Schlapp, 1915),[326] and one of the arguments for congregating large numbers of residents had been that this would facilitate research. This potential has never been fulfilled except at a very few institutions at a given time. Even today, very few are making a well-sustained, active, and significant research contribution to the field.

One goal often achieved by institutions was that of providing relief to families. But even here we have an element of irony in that family relief could often have been achieved better and cheaper by measures other than institutionalization.

If my formulations and interpretations are correct, we can summarize the trends in United States residential services to the retarded as follows, and as depicted in Figure I. Attitudes toward retardation paralleled those toward a number of other deviancies. Around 1850, a developmentally oriented residential model attempted to return deviant people to the community. Between 1870 and 1890, this model was replaced with one based on pity which called for protective isolation of the retarded. This period was brief, and was soon succeeded by one emphasizing the menacing nature of deviancy. Certain trends that had originated during the pity period were accentuated, so that retarded people were congregated into huge groups, sequestrated from society, segregated from other retarded persons of the opposite sex, asexualized, and dehumanized in poorly supported, inhumanely run regimented institutions. The puzzling and anachronistic mode of functioning of today's institutions can be understood if we see them as having been maintained by a tremendous amount of momentum but bereft of rationales for about 40 years.

The problem of residential services cannot be solved by working on a number of specifics at a time, or by calling for simple-minded, low-level measures such as more money. All the money in the world will not change the minds of men. What we need are concepts and models. The current model, the entire system, as Howe called it, is inconsistent with contemporary perception of the nature and role of the retarded person in our society. Such new and viable ideology (e.g., the principle of normalization) is gaining wide acceptance. With the acceptance of this new ideology, we are witnessing the agonized death struggle of an institution model based on a perception of retarded persons as a menace and/or subhuman organism.

The greatest irony lies in the fact that the founding fathers foresaw much of what happened, and repudiated the trend institutions were taking within 20 years of their founding. H. B. Wilbur (1879)[327] stated that he had always been in favor of building specialized institutions rather than enlarging existing ones for multiple purposes. In 1866, when Howe gave the dedication speech for a new institution for the blind in Batavia, New York, he virtually repudiated this institution at its very beginning, and as the guest of honor, this courage and conviction cannot be overemphasized. Everything he said applies to the institutions for the retarded as well.

"As it is with individuals, so it is with communities; and society moved by pity for some special form of suffering, hastens to build up establishments which sometimes increase the very evil which it wishes to lessen.

"There are several such already in this country; and unless we take heed there will be many more. Our people have rather a passion for public institutions, and when their attention is attracted to any suffering class, they make haste to organize one for its benefit.

"But instead of first carefully inquiring whether an institution is absolutely necessary, that is, whether there is no more natural and effectual manner of relieving the class; and afterwards, taking care that no vicious principle be incorporated into the establishment; they hastily build a great showy building, and gather within its walls a crowd of persons of like condition or infirmity; and organize a community where everything goes by clock-work and steam. If there be a vicious principle in the organization, as of closely associating persons who ought to live apart, it is forgotten in admiration of contrivances for making steam do what once was done by the good housewife, with her cook and maid; and of the big bright coppers, the garish walls, and the white floors.

"But no steam power, no human power can long keep a vicious peinciple from cropping out. It has done so in many European institutions of charity; it will do so in many of ours . . ."[328]

" . . . Grave errors were incorporated into the very organic principles of our institutions . . . which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils. Let me set forth a little my idea of the general principles which should underlie all such establishments, and which have been too much neglected in the organization of many of our public institutions.

"All great establishments in the nature of boarding schools, where the sexes must be separated; where there must be boarding in common, and sleeping in congregate dormitories; where there must be routine, and formality, and restraint, and repression of individuality; where the charms and refining influences of the true family relation cannot be had—all such institutions are unnatural, undesirable, and very liable to abuse. We should have as few of them as is possible, and those few should be kept as small as possible.

"The human family is the unit of society. The family, as it was ordained by our Great Father, with its ties of kith and kin; with its tender associations of childhood and youth; with its ties of affection and of sympathy; with its fireside, its table, and its domestic altar—there is the place for the early education of the child. His instruction may be had in school; his heart and character should be developed and moulded at home.

"Artificial families have been tried and found wanting. Communities in imitation of the natural family, especially those confined to one sex, are fertile of evil . . . Witness soldiers in detached garrisons; sailors on long voyages; prisoners under long sentences. Wherever there must be separation of the sexes, isolation from society, absence of true family relation, and monotony of life, there must come evils of various kinds, which no watchfulness can prevent, and physician can cure.

"We should be cautious about establishing such artificial communities, or those approaching them in character, for any children and youth; but more especially should we avoid them for those who have natural infirmity; or any marked peculiarity of mental organization.

"Let me dwell upon this, for in my view, it is very important. Such persons spring up sporadically in the community, and they should be kept diffused among sound and normal persons. Separation, and not congregation, should be the law of their treatment; for out of their infirmity or abnormality there necessarily grow some abnormal and undesirable effects, and unless these be counteracted by education, they disturb the harmonious developments of character. These effects are best counteracted by bringing up the child among ordinary children, and subjecting him to ordinary social and family influences; but, on the contrary, they are intensified by constant and close association with children who are marked by the same infirmity of peculiarity . . . We should therefore keep this truth in mind; and give it due weight when forming plans for the treatment of any special class of persons.

"As much as may be, surround insane and excitable persons with sane people, and ordinary influences; vicious children with virtuous people and virtuous influences; blind children with those who see; mute children with those who speak; and the like.

"People run counter to this principle for the sake of economy, and of some other good end, which they suppose cannot be had in any other way; as when they congregate the insane in hospitals, vicious children in reformatories, criminals in prisons, paupers in almshouses, orphans in asylums, blind children and mute children in boarding schools. Hence I begin to consider such establishments as evils which must be borne with, for the time, in order to obviate greater evils. I would take heed, however, against multiplying them unnecessarily. I would keep them as small as I could. I would take the most stringent measurements for guarding against those undesirable effects which lessen their usefulness; and for finally dispensing with as many of them as may be possible.

"But, besides this general objection to such establishments, there is another and more practical objection to the method of congregating . . . any class of young persons marked by an infirmity like deafness or blindness. They depend more than ordinary persons do for their happiness and for their support upon the ties of kindred, of friendship, and of neighborhood. All these, therefore, ought to be nourished and strengthened during childhood and youth—for it is then, and then only, that they take such deep root as to become strong, and life-lasting.

"The home of the blind and of the mute should be his native town or village; there, if possible, he should live during childhood and youth; there he should form his friendships; there, if he comes to need special aid it will be given most readily and fitly; and there his old age will be cherished.

"Beware how you needlessly sever any of those ties of family, of friendship, of neighborhood, during the period of their strongest growth, lest you make a homeless man, a wanderer and a stranger. Especially beware how you cause him to neglect forming early relations of affection with those whose sympathy and friendship will be most important to him during life, to wit, those who have all their senses; and how you restrict him to such relations with persons subject to an infirmity like his own.

"I would observe, by the way, that the necessity now felt for a new institution in your state has arisen, partly at least, from radical faults in the organization of the old one, which necessarily led to faults in its administration such as I have noticed. If the conditions of admission had been such as to exclude some who entered, but who ought not to have entered; if stringent measures had been taken to prevent the multiplication of graduates in and about the institution, and to encourage their dispersion and settlement in the several towns, instead of leaving them to congregate in the commercial capital, and to besiege the political capital; if these things had been done, the state would perhaps not now be called upon to incur the cost of building and the continual expense of carrying on a second institution.

"But, it is settled that you are to have one, and, I trust, it will become worthy of the generous motives which prompt its erection; and of the great state which is to build it.

"Take heed that it shall be organized on sound principles; and while copying all the good features of existing institutions, avoid those which are not good. Those establishments are all faulty. Not one of them is worthy to be your model in all respect; and the persons who flatter themselves that their favorite one is worthy to be copied exactly, are blind to faults which can be seen by looking beneath the surface. Never mind their showy buildings and special accommodations; you may as well measure the morality of a family by the structure and arrangement of its dwellinghouse, as test institutions by their mechanical advantages; but look at the principles and system by which they are conducted. You will, then, find they are faulty in many respects.

"They are generally wrong in receiving pupils too indiscriminately; being, in most cases, tempted to do so by the fact that they are paid according to the number they receive. They are wrong in receiving all pupils as boarders, when they should receive only those who cannot board at home, or in private families. They are wrong in associating the blind too closely, and too many years together, thus loosening or breaking the ties of family and of neighborhood—segregating them from society—forming a class apart—creating a feeling of cast—and so intensifying all the unfavorable effects growing out of the infirmity of blindness . .
They are creating the necessity, or the demand, for permanent life asylums; all of which consummations are devoutly to be prayed against.

"Instead, then, of copying the existing institution, I think that in organizing a new one something like the following rough plan should be adopted: If the field were all clear, and no buildings provided, there should be built only a building for schoolrooms, recitation rooms, music rooms and work shops; and these should be in or near the centre of a dense population. For other purposes, ordinary houses would suffice" (Howe, 1866).[329]

Howe also repudiated the trend from education to pity: ". . . aid should not be given in alms, or in any way that savors of alms. Were it possible for government to pension every blind person for life, that would probably do more harm than good. We are safe in saying that as far as possible, they should be considered and treated just as ordinary persons, our equals and friends, are treated, and not singled out as special objects of pity. This is too often forgotten" (Howe, 1866).[330]

It was as if the founder himself was saying: "Stop it, you fools; we have made a gigantic error!" Alas, Howe had been 100 years ahead of his time, and his cautions went unheeded.

Seguin is probably the best-known figure in mental retardation in this country. He was brought by Howe from France, was instrumental in the founding of about a half-dozen of our early institutions, and was co-founder and first president of what is now the American Association on Mental Deficiency. Yet Seguin (1870),[331] too, disapproved of the trend of things in 1869, and of the developing isolation of the institutions. ". . . In locating these schools through the country . . . they have put them out of the reach of concourse of scientific men and means, which are concentrated in capital cities . . ." "This necessity of the situation—for, if these institutions do not progress, they will retrograde—demands of the selection of a suitable place among scientific surroundings; the direction of a man who understands the philosophy of the labor, the selection of microscopists, anatomists, psychologists, young medical men eager for study, devoted women ready to teach, to nurse, and to acquire the capacities so much wanted in other schools. With this force at command, there will be treated, besides the question directly relating to idiocy and medicine, those which touch society through education. It is not a minute too soon.

"From all the points of the compass, steam and electricity accumulate men and ideas on this continent that will soon be, for good or evil, the new world, new for evil if the comers invade us, not by the sword, but their low spirit of submission to Eastern or Western bonzes; new for good, if we are ready, with a powerful physiological system of education, to assimilate them, women, men, children, of all races and colors, to our unity and independence . . ."[332]

In 1878, Seguin added: " . . . if ideas create architecture, architecture reacts upon its mother-idea, to develop, distort, even kill it (as it appears by the influence that the latter form of the insane asylum has exercised on the theory and practice of the treatment of insanity). Truly, the ideas, too soon cast in brick-form, shrink by compression; and the monument erected for their development becomes too often their empty sarcophagus. . . ."[333]

The remarkable thing is that our experience has been shared by many countries that built large institutions in the last 100 years. It seems as if the very model, as we have known it, is unworkable.

If it is a universal fact that this model has failed, perhaps the institution built on it is not the solution to our problems. Perhaps the institution as we know it is unworkable and cannot be salvaged no matter how much money we spend.

In Greek mythology we encounter a somewhat overly friendly character by the name of Procrustes. He wanted very much to be a good host to weary wayfarers, and when a traveler journeyed past his dwelling, Procrustes would insist that he stay the night with him. After some wining and dining, Procrustes would show his guest to his bed. Trouble was, there was only one bed, of one certain size, and Procrustes was a perfectionist. The bed just had to fit the guest. So if the guest was tall, Procrustes chopped off his legs until guest and bed were exactly of the same size. If the guest was too small, the host strapped him into a rack and lengthened him out a few inches. Obviously, by doing things his own way, Procrustes was prepared for all comers.

The moral of the parable: our institutions have been Procrustean. It did not matter who or what the resident was, whether young or old; whether borderline or profoundly retarded; whether physically handicapped or physically sound; whether deaf or blind; whether rural or urban; whether from the local town or from 500 miles away; whether well-behaved or ill-behaved. We took them all, by the thousands, 5,000 and 6,000 in some institutions. We had all the answers in one place, using the same facilities, the same personnel, the same attitudes, and largely the same treatment.

And if our guest did not fit, we made him fit!

What we need to do is take an entirely fresh look at the needs of retarded people and increase the goodness of fit between their needs and our programs. And we must face the possibility that we may need a new bed.

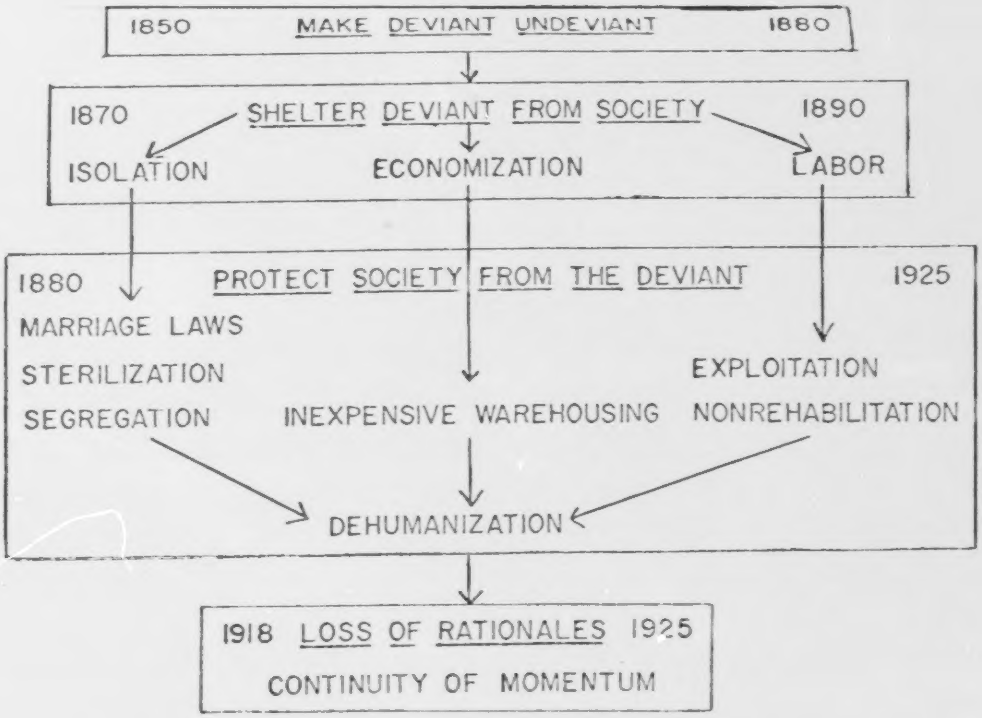

FIGURE 1: Graphic Summarization of the Evolution of Institutional Rationales and Practices

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Biography

WOLF WOLFENSBERGER was born in Germany in 1934 and migrated to the United States in 1950. In 1962, he received a doctorate in psychology and special education from George Peabody College for Teachers in Nashville. His work roles have included those of clinician, administrator, researcher, and teacher in mental retardation and human services.

From 1964 to 1971, he was a mental retardation research scientist at the Nebraska Psychiatric Institute in Omaha; from 1971 to 1973 he was with the National Institute on Mental Retardation in Toronto, Canada, as a visiting scholar.

Currently, Dr. Wolfensberger is professor in the division of special education and rehabilitation at Syracuse University, New York, and director of the University's training institute for human service planning, leadership, and change agentry. Recent interests include systematic planning of human service systems, implementation of the normalization principle and of citizen advocacy, and reform of the system of services for elderly citizens.

4. A Perspective

Ruby Luna

I was born Ruby Baca Sedillo in 1937 in La Joya, a place that is now just a bend in the road in central New Mexico. Before I was three, my parents split from one another and from me and I was raised by my grandparents. I took my grandfather's name, Baca. When I was four, we moved to Las Cruces where I grew up and went to school.

I married Luis Luna in 1957, when I was 20 and one year out of high school. Luis was a sophomore at New Mexico State University, preparing to be a teacher. We had five children in eight years: Denise, December 7, 1957; Mark, June 2, 1959; Cindy, October 20, 1960; Laura, May 1, 1963; Jason, January 8, 1965.

Our first two children were normal but when Cindy was born I knew from the way the nurses were acting that something was wrong. She was born in Albuquerque where we were living at the time. The nurses did not bring her to me the first day; they told me it was because she was very small and in an incubator.

The doctor didn't come in until about twenty-four hours after she was delivered. He told me, "We think there may be a problem with your baby. She has a very small head, and we think she may be mentally retarded. We have called in a specialist to examine her, and we'll know more by this evening."

After the specialist saw her he said she might have brain damage but we couldn't be sure until she was a year old. I still hadn't seen Cindy, and they still wouldn't bring her to me. I had to tell Luis what little the doctors had told me, and Luis made me get up and walk down to the nursery to see her. Our first reaction was that she didn't look all that bad, after what we'd imagined.

I now know that Cindy was obviously microcephalic at birth, and the doctors must surely have known it at first glance. Their problem was not in diagnosing her, but in levelling with me and Luis.

When Cindy was three months old, Luis got a job teaching school in Dulce, a village on the Jicarilla Apache Reservation in the mountains of northern New Mexico. Dulce is 100 miles in any direction from the nearest city. So there I was, four years out of high school, with three children under the age of three, one of them "possibly" retarded. That year we seized on every indication that Cindy might not be handicapped. She was growing and she sat up normally, and we built many hopes on things like that. But her head was small, and Luis had a distant cousin who was microcephalic, so we knew that such a condition could exist.

Beyond that, I knew nothing. In those days you didn't even see retarded people out in public. I had been married a year before I met or even knew about Luis's cousin, who was about 14 then. He was not hyperactive or destructive in his behavior and nothing much was expected of him, so he was not a source of stress in his family. They treated him kindly and he was part of the family, but as a pet is part of a family. Pets are not respected or treated with the dignity we accord to people. He had received no training; his status was low; he was tolerated.

I had expectations for my children, and when Cindy was born all I could think of was, "Now we have a pet in our family." But I rebelled at accepting that a child of mine should have that status. My lack of exposure to handicapped people made all of this harder, and the exposure I did have, to Luis's cousin, probably didn't help, since it offered no example of positive achievement.

When Cindy was a year old we took her for evaluation to a federally funded center in Santa Fe. They gave her two hours of tests and examinations, then they told us that afternoon, for the first time since she was born, that she was definitely retarded. They also said, "We can't tell you the results of the tests now, her IQ and how well she might function. We'll compile the results and send them to you."

It didn't occur to us to demand better answers on the spot, in terms at least of our practical problems. We simply went back to Dulce and waited. A few weeks later, instead of receiving the test and evaluation results directly from the center, a public health nurse called me into her office. She had the results of Cindy's tests but, she said, it was "against regulations" for parents to see the records of their children. So she read through the records silently, and then turned to me and summarized and interpreted the findings. I had to go home and tell Luis because he hadn't been able to go with me.

Nothing she said meant anything to us. We didn't know what Cindy had been tested for; we didn't know what to ask the nurse about the findings; we didn't even know what we wanted to know. We did sense that the nurse was being very condescending to us, but we didn't realize that we could have protested strongly about that.

We settled down to cope with the problem on our own. Laura was born next, a normal child, so I had four small kids at home. Cindy soon began walking and she was also becoming extremely hyperactive. And I was pregnant again.

The attention we had to give Cindy, and the turmoil she caused, were affecting the older children. They began having emotional problems in school, bedwetting, things like that. I saw myself losing control of my family if we didn't do something. Then, and for a long time, I was on the edge of going berserk.

The only services we could learn about for retarded children were provided in a state institution. We also heard that a family who applied could wait several years before their child was admitted because there were more than 300 children on the institution's waiting list. Soon after we applied, however, the state opened another facility and moved quite a few children there from the institution. Then, seven months after we had applied, they accepted Cindy.

We couldn't get a babysitter when they notified us, so the whole family drove the 200 miles from Dulce. At that point I was not expecting Jason for another two weeks, but I started labor at the institution during the two hours or so when we were admitting Cindy. Seeing Cindy being led away from us, down the long corridor of the administration building was, to put it mildly, an exceedingly traumatic experience. I will always believe that those pressures led me to start labor.

We drove back to Dulce, where we did get a sitter for the other three kids and then on another 100 miles to Farmington where the doctor I was then going to practiced. We made it, in a midnight blizzard, and Jason was born the next day.

I saw Jason when he was born and by then I had at least had enough experience to diagnose him myself immediately: another microcephalic child. Again, for some reason, I didn't get to talk to the doctor for about 24 hours, and when I did talk to him I spared him the trouble and told him the diagnosis myself.

Beyond that, I was emotionally numb. I didn't want to talk to the doctor or to anyone else; I didn't think anyone could help me. Then and for the next several months, the only way I could hold myself together was to function from minute to minute and not allow myself to think further than that.

We had had our children in ignorance, and we accepted and loved them as best we could in spite of the burdens we were not prepared for. But one thing I had already decided before Jason was born, and before I left the hospital in Farmington I was sterilized by tubal ligation. I was just 27 then.

So literally the day after we placed Cindy in the institution, we were back with three normal kids and one retarded infant.

When Cindy entered the institution they told us it was a "regulation" that parents couldn't see their children for the first six weeks. We hadn't expected anything like that and we were dismayed, but also quite intimidated, so we did not question it. At the end of the six weeks, we drove the 200 miles down from Dulce. At the institution they told us we couldn't see Cindy for still another six weeks, because her cottage was quarantined for chickenpox. No one had bothered to call us, and we certainly hadn't thought to call ahead. After that, however, we began to phone regularly for information on Cindy's progress.

The children at the institution are grouped in cottages. Cindy's cottage, for example, housed about 30 children. For each cottage, one social worker was assigned to be the contact between those children and their parents. When I began calling the social worker for Cindy's cottage, I got a standard, cheerful, response: "She's just fine, she's eating well, and they're taking good care of her." That same answer, week after week, with no more detail, made us uneasy. So on about the tenth call, I asked the social worker when she had last seen Cindy.

She said, "Oh, I was down at the cottage and saw her just last week." That, from a professional whose job was to report to parents on the kids in that cottage. I found some words for my fears and indignation. The social worker quit being cheerful and friendly. She told me, in effect, "Look, lady, I'm very busy. You brought your kid down here, now get out of my hair, quit bothering me."

Events like that convinced us that no matter what else happened, we had to get closer to Cindy than the 200 miles from Dulce. Luis found a job teaching school in a small town a few miles from the institution. That solved the distance problem. But he had to take a $1,000 cut in pay, and that was virtually a disaster for our family at that point. A year later he got a better job with the State Department of Agriculture in Albuquerque, still within easy driving distance of the institution.

We brought Cindy home regularly on weekends and two things we noticed upset us terribly: she had large, quite bad and long-lasting sores, mostly around her mouth. Much worse, often when we picked her up, she had fresh bruises on various parts of her body. The cottage staff at the institution, the people in direct daily contact with the children, were nonprofessional (and quite low-paid) attendants. We asked them about Cindy's sores. The answer was, "All the children have those sores. There's nothing that can be done about it. Every Monday morning the doctor sees any of these children who we feel need attention." We asked about the bruises and the attendants said, "All the kids fight among themselves." The most upsetting thing was the casual tone of these responses, conveying quite clearly that sores and bruises were not considered to merit concern.

A brother of one of Luis's friends worked on the administrative staff of the institution. One Sunday afternoon when we took Cindy back to the institution, we ran into him in the parking lot. We got to talking, and we brought up our anxiety about Cindy's condition. He came over to the car and looked at her, and it obviously bothered him a great deal. He told us he would look into it and see that something was done.

A few days later I received a formal letter from a lady, I am sure a very nice lady, who happened to be chairman of the state board that was responsible for the institution. The letter said that the institution was doing the very best possible for the children there, and if we had any complaints perhaps we had better take Cindy out. If she stayed, and we had any problems, they were to be referred to the staff physician, and we were certainly not to talk to other personnel again. The letter ended with the statement, again, that it was our prerogative to take Cindy out of the institution. This "invitation" was, of course, a great threat to us. The letter achieved its purpose, because for sure we did not do a lot of complaining about the institution after that.

But Cindy was still there and what do parents do in that kind of situation? We, and other parents, did just one thing: we closed our eyes to the situation in order to survive. You have to live day after day, not knowing what your child may be enduring, seeing signs of possible abuse and neglect, and ignoring it. That is not easy.

Today, I believe a lot of parents with children in the institution are still doing that, although the place has improved. The parents are going one step further; increasingly, they are lobbying for more money for the institution. They will probably get it, and it will make them feel better, because the institution can be made a much better place. It will still be a warehouse for their children, but it will be a much better warehouse.

We had a whole set of feelings then that certainly made it easier for the institutional people to manipulate us and keep us outwardly docile. We felt tremendous guilt at having produced burdens to society in the form of handicapped children. We could no longer stand on our feet as an independent, self-supporting family, but had to swallow our pride and go around begging for help. Then, it was made clear to us the only acceptable reaction was for us to show gratitude for the help extended, regardless of the quality or effectiveness of the services. I have come to call this attitude shown by some officials toward parents the "better than nothing" syndrome.

By the time we moved to Albuquerque I was getting plenty of signs that my emotional resources were running out. There I was in a totally new neighborhood, and one thing I have never had any use for is housewives running around to one another's back doors, full of talk about their problems. Yet that's exactly what I found myself doing: going around to complete strangers and spilling out all kinds of details about the things I couldn't handle with my family.

That was bad, but there was worse. The road to the institution in those days made a sharp turn at one point and crossed the railroad over a high, narrow wooden bridge. Late one Sunday afternoon in winter, with the daylight fading, I was taking Cindy back to the institution after spending a weekend at home. I had Jason in the car too because no one was home just then who could take care of him. Approaching that sharp turn I had the thought that I could speed up and drive the car off the bridge and that would take care of all the problems as far as Cindy and Jason and I were concerned. The rest of the family would get along somehow and perhaps better.

It took a lot of effort not to do it. Once across the bridge the road was flat, and on the way home it was just Jason and myself, which wouldn't have solved the problem. So it was an impulse of a moment, but it was so strong that I knew afterward that I was in real trouble and had to get help of some kind.

I located the County Mental Health Center in the phone book. Since they declined to treat me alone, Luis and I went once a week for two years of therapy. First, this was individual therapy and then it became group sessions. The therapy did some good: I gained a little self-confidence and saw that I might be worth something. The therapy also helped me to admit what I couldn't before: that I didn't like the mother role, even though no other role seemed open to me. I could easily have been a good mother to three normal kids, and perhaps an excellent mother to just one kid. But I was totally unable to cope with two retarded kids in addition. I was extremely messed up during that time, still deep in the business of asking, "Why me?" and going back over my past sins, asking which ones could have been bad enough that I should be paying for them the way I was.

The other think that was driving me mad was Jason's behavior. He was about two then, hyperactive, didn't sleep day or night, and threw repeated tantrums. Therapy wasn't the answer for that. I found a prospective new source of help at a center I will call "Agency A" in the form of counselling on methods for coping with these behavior problems.

Counselling was a long, slow business and, unfortunately, it was a progressive disaster for me. The counsellor obviously wanted to help me. Here was this brilliant and dedicated person who had the answers to my problems, and kept trying to tell me the answers. She tried many approaches, and in her office they seemed to make sense.

At one point, for example, she advised me to count successive episodes of Jason's behavior to help me make my own behavior more "consistent." There I was, not even in shape to decide which of Jason's shoes to put on first, and I was to go home and keep a record of his behavior, and try to be "consistent." Within an hour or so Jason, who really had my number from the day he was born, would have the household in complete disarray again. As it got worse, I felt increasingly guilty about my inability even to convey to the counsellor that it was getting worse. I began to dread having to go back each week and "confess" my continuing inability to control my son's behavior.

A good part of the problem I now feel, was that the counsellor's answers to my problems were devised solely in the antiseptic surroundings of her own office. She never saw Jason, never saw my home. Thinking back now, I wonder if she really saw me!

The counsellor's appearance and manner were always completely professional. I felt the coolness, and reacted the way the system—I hope not the counsellor—intended: I agreed, in effect, that the counsellor was my superior, and that I was inferior. The problem had to be that I was so inept that I couldn't apply her wisdom. Counselling thus became just another burden, and I kept on with it in spite of my negative reactions because I needed something to cling to and that was all there was just then.

It was not just that one counsellor. All the professional therapists and counsellors I encountered in those days made me feel that my problems were essentially clinical and therefore remote from their personal concerns. They met these crazy mothers for eight hours a day, did their best, and then went home and didn't see anyone else the rest of the day who was suffering the way I was. In particular, they didn't live with the handicapped child who was the problem. That's unfair, of course. Everyone has problems, professionals included.

I no longer approach professionals with blind respect, although my friends and I still need their services. Now I demand that professionals be warmly supportive, that they be able to interact with me in ways that allow us to have and show personal feelings about one another, and never mind the "techniques." I don't see how professional help can work otherwise.

Up to that point, I had found no one who had any practical help to offer me with Jason. The thing that did help started with a phone call from a woman I'd never heard of, Ruth Miksovic. She had gotten my name somehow and said she was running a preschool for kids like Jason, and would I like to bring him? That was absolutely the first indication I had had in years of continuous encounters with doctors, social workers, the institutional staff, therapists, and counsellors, that there were some services available in the community that might meet some of my children's daily needs.

Ruth's preschool operated half-days only and it was too far from where we lived to drive back and forth both ways. So I took Jason and waited at the school in a room next to the classroom during the half-day. There I began for the first time to meet other parents of handicapped children.

That was potentially helpful; today, I recognize other parents as by far the best source of help, although I do not discount good supportive therapists. But these parents baffled me. They had the same problems I had, or even worse problems. It seemed reasonable to expect they would have some similar feelings. Instead, they all seemed incredibly well-adjusted. I think the parents I happened to encounter at Ruth's school all did fit the mother role much better than I did. To that extent, they were better adjusted.

But since then I have had much experience with parents of handicapped children, and I know we all share some strong feelings, particularly of deep anger and insecurity. We also share rejection by the rest of the world, as we are reminded by startled looks and nudges and whispers whenever we take our handicapped children out in public or to the doctor. (Going out in public with one handicapped child is painful enough. You can imagine what it's like when we are out with both of ours.)

There is also a lot of love in these parental feelings, fortunately, but it is mixed up with the anger and fear and rejection and society is not ready to hear that we have such feelings. So parents of handicapped children make great efforts to hide their "unacceptable" feelings and to appear well-adjusted. I had had much the same conditioning, but I was a little less willing to settle for appearances.

I finally found one other mother who did open up as we became acquainted and, in the course of time, absolutely levelled with me about her negative feelings. I drew her out, but I also had the good sense to listen and never to judge or condemn her. So we became therapists for each other and she is now one of the best therapists I know of for other mothers.

More good things happened, not all of them in the sequence I am describing here. One day a woman, representing two community centers serving the low-income sections of Albuquerque, knocked on my door. She said that Agency A, the organization that had provided my counsellor, was working through the two community centers to get a group of parents of handicapped children to meet and talk about needs they might share for education and other help for their children.

I told her Jason was in Ruth's school and Cindy was in the institution and I didn't need any help. I believed that, because I didn't have the slightest idea what else could help. Also, by temperament, I was not a joiner, and being asked to meet with a group seemed just one more unnecessary demand on my energy. But I did go to the meeting, perhaps because I liked the woman's manner. There were about 50 parents there, a few professionals from Agency A, and people like a religious Brother who was running a home for handicapped boys.

That first meeting became purely a gripe session. All the parents had kids who were at home without services. Albuquerque Public Schools wouldn't take them, the Association for Retarded Children was running a small day-care center then but was very selective and took only a few kids, so these parents represented the ones who were not being helped.

I said very little at the first session, but I did go to the next meeting where it became clear that some problems had been identified; also, that it was going to be up to the parents to do something about them. I began to speak up a little, and I think I was helped to do that by the experiences I had had in group therapy. At the third session, I was elected Vice President. We named our organization, "Esperanza Para Nuestros Ninos (Hope for our Children)," and took steps to become a legal corporation. At the fourth meeting the professionals dropped out almost entirely, I believe according to their plan, and left it all up to us parents, to sink or swim. I don't think the professionals really expected us to get anyhere either.

Our meetings continued through the fall of 1968 and early 1969. That winter we raised $35 by cutting Christmas trees in the mountains and selling them in town. The following summer we started a very limited recreation program for about eight severely handicapped kids. The staff consisted of unpaid parents and some volunteers being trained in a program for paraprofessionals at The University of New Mexico.

In the fall of 1969, Agency A came back into the picture by securing a grant from the local Economic Opportunity Board to operate a school program. We parents got the necessary building, which was an empty barracks that had once served as an extra classroom at one of the public elementary schools. Agency A hired two part-time practicum teachers for about 12 children and ran the program for us. They ran it to the extent that we were not even allowed to see the budget, much less have a voice in what was done or how it was carried out. Agency A did recognize the existence of Esperanza parents to the extent that they encouraged us to meet once a week or so and talk. But with no power or control over the program, talk about what?

That year I entered Jason in Esperanza; he was then five. We had plenty of problems with Jason at home but some also developed with Esperanza. When I approached Agency A's director of the Esperanza program, I got an answer, with a familiar ring, in the most polite, controlled and professional tone of voice: in effect, "If you don't like the program, you can take your child out of it." Other parents were getting the same brushoff whenever they raised objections or questions.

We parents had gone too far together to accept that situation and the following year we took over Esperanza ourselves with funding we scrounged from a variety of sources and a lot of donated help in kind. We provided a program for about 18 kids. We didn't know much but we knew we had to have certified special education teachers; we found and hired two of them. We knew we needed a speech therapist; we found enough money to bring one in for about one-quarter time or less. We also thought we had to have a professional director; we found a Ph.D. candidate in special education and hired him half-time. We soon noticed that about the only time he appeared at the school was to pick up his paycheck. We fired him after two or three months and put the money we thus saved into hiring one more teacher, who we desperately needed. I became the director and have been ever since.

The following year, 1971–72, among other sources of funding, we began contracting with Albuquerque Public Schools to educate some of the applicants for their special education classes. We were providing services (and we still do) for kids who had been rejected by the public schools and by about every other program in town. We were slowly and painfully expanding. We still had no infant program, for example, which we now know is one of the most important of all services. We had insufficient speech and physical therapy; we hadn't even learned how important occupational therapy can be for kids with neurological damage, which includes virtually all those enrolled with us.

We have continued to expand and now in 1975 we are serving for 12 months a year 95 severely handicapped children, ranging in age from newborn infants to teenagers. We have a staff of over 50 teachers, therapists and aides and we are attracting professionals and students from New Mexico and beyond the state as visitors, volunteers, and consultants. This year, for the first time, we also have a formal program funded by the U.S. Bureau of Education for the Handicapped to demonstrate our methods to other groups of parents and professionals. Children are referred to us by local hospitals, the public schools, state institutions for the handicapped and other state agencies, University programs, and private physicians; virtually every group that might encounter a severely handicapped child.

Of course, we didn't do all this alone. A few professionals did come forward even in our early days to help us with ideas and practical advice. As we have gained visibility, many more professionals have joined or helped in our programs. But our parents still control our Board of Directors and set our policies.

Looking back, I can see several stages that Esperanza has gone through in gaining recognition from agencies and professionals:

1. We were ignored.
2. We were tolerated.
3. We aroused jealousy (some of it continuing today).
4. We gained grudging acceptance.
5. Today we finally enjoy thoroughgoing respect and recognition.

As Jason approached school age I was determined to get him into the public schools but the difficulties were considerable. Albuquerque Public

Schools were then accepting students for special education classes, usually only after they were seven years old. They provided special education at only one location and they were extremely demanding about the children they would accept and who would fit into their category of "trainable mentally retarded." The child had to be completely toilet-trained, able to feed and care for himself, not be disruptive, and be able to contribute to the group. As one of our Esperanza teachers said: "They don't want them 'trainable,' they want them trained." The schools have improved vastly since then and they now accept many kids they wouldn't even have looked at in those days.

While Jason was still a holy terror at home, he could conform very well in a tightly structured situation like a well-run classroom. He was by no means toilet-trained at home but that was my problem. I hadn't known how to train him at the right time and during that time I was highly disturbed myself so I was spoiling him rotten to make up for the ways I imagined I had let Cindy down. We had plenty of evidence that he could control himself but Jason knew very well how to play games with me so we also had plenty of accidents at home.

Under those circumstances I was damned if I was going to let them keep Jason out of the public schools. I told them he was toilet-trained and gambled that the classroom structure would make it so and that we could explain away any occasional accidents.

They accepted him at the age of six and it turned out that he stayed quite well trained at school. Then he would come home and have a minor nervous breakdown every afternoon, including loss of his toileting control.

Jason spent three years in special education classes. During most of that time I assumed that these home problems were purely behavior problems and that I was to blame. If he was well controlled at school and kept coming home and falling apart, what else could I believe?

Then we began to get acquainted with occupational therapy at Esperanza, the specialty that helps the neurologically impaired to develop control over their muscular actions and body movements. We were already using speech therapists and were using physical therapists to help some of the children overcome orthopedic problems affecting their bones and muscles. Now I saw occupational therapy help hyperactive and other children who had neurological damage.

In the spring of 1973 I brought Jason to Esperanza for evaluation of his hyperactivity. We found that a lot of what we had thought was purely behavior problems were partly neurological. He is spastic in many parts of his body and when we found that out we moved him to Esperanza from April to September of that year for combined physical and occupational therapy.

By mid-summer we had a different kid at home. When you have been living with someone whose behavior is simply terrible all the time and he changes you are going to notice it. The other children kept remarking on it, to say nothing of Luis and myself. Jason was becoming calmer, his speech was clearer, and he was able to concentrate at home for the first time. So that fall we re-entered him in the public schools with great expectations for further progress. Instead, he began regressing and soon he was back to his April standard of behavior at home.

That presented Luis and me with a lot of new conflict. We were satisfied that Esperanza was a superior program for severely handicapped children, but Esperanza had a policy, and still does, that any child over six years old who could be admitted to the public schools should be. Our parents still have mixed feelings about the public schools; but basically we believe in the public schools and want to strengthen them. We want our kids in them whenever possible. Esperanza does a great deal of referral back and forth with the public schools. We seldom have any problem in agreeing with the school people about whether a particular kid can do better in the public schools or in Esperanza. With Jason, maybe I stretched that policy but I brought him back to Esperanza for the services I knew he needed and he is there now.

We also had to resolve Cindy's future. I give the institutional staff credit for recognizing long before we did that the time was approaching when she should leave the institution. In 1971 she was 11 years old and had been there seven years. She had become one of the elite kids, a pet of the staff. She was one of the highest-functioning girls in her cottage, could make beds neatly and be counted on to deliver notes across the campus, things like that.

When the institutional social worker came to visit and to sound me out on the idea of returning her home, she left me extremely upset. I felt that both I and my family were still far too disturbed for such a move. Jason was still a constant source of turmoil in the family; I was still fumbling through my own conflicts and just beginning to get seriously involved in Esperanza.

The institutional people raised the question but didn't force it. Luis and I felt new guilt over our unwillingness to bring her home immediately. It took us a full year to psych ourselves into that step. As we thought it over I became convinced that if she were to come home, she would have to be admitted to the public schools and, as with Jason, that was by no means assured in advance. But we did apply and after an initial turndown she was accepted when a vacancy appeared in one of the classes. She came home in 1972 and has been home ever since and is still in public school.

Through Jason and Cindy we met other parents with kids in special education in the public schools. Nearly all those parents were so fearful of losing what benefits they had that they automatically resisted any change. The public schools wanted to expand their special education program but that would mean bussing many kids a long way across town to a larger building. The parents called an indignation meeting to shoot down those plans. The new school would be next to an elementary school and the parents expressed a lot of feelings that elementary kids were cruel and that their handicapped children would be taunted and harmed.

I appeared to be the only parent at that meeting who supported the public schools. I told the other parents that Esperanza had been housed on the grounds of one public school or another ever since it had been started and that Esperanza children, generally far more severely handicapped than theirs, had simply not been the targets of any teasing incidents serious enough for our staff to recall. My arguments, I believe, helped to change the course of the meeting. The public schools went ahead and now those special education students freely share the playground and cafeteria with students in the regular classes. The public school people were grateful to me and that has helped communications between the public schools and Esperanza.

The parents had been upset because they were up against something unknown. They didn't have any way to evaluate this new program they were being offered and they could imagine only the negative possibilities. I believe parents must be offered training to allow them to evaluate schools for themselves. I will be happier about Esperanza when our parents can do just that. Right now, our parents have faith that we are a good school for their children but I would like them to have a systematic checklist of things to look for, things to ask the teacher, things to tell the teacher, and the knowledge of how to apply and interpret that checklist.

I naturally have by now some strong feelings about services for the handicapped that are operated by professionals, versus services that are controlled by parents. From what I have seen, I feel that services that are operated by professionals are also likely to be operated primarily for the convenience and interests of those professionals, although I know of some very worthwhile exceptions to that rule.

I feel that Agency A, for example, probably started the parent meetings in 1968 and operated Esperanza in 1969–70 to show "community participation" to get support for the agency's own research and teaching programs. Some good things certainly did come from the parent meetings. I believe the agency must also be making some contribution in its research and teaching activities. But I do find it difficult to accept that they are not heavily involved in direct delivery of services to the handicapped. From my viewpoint, I wonder how else you can expect to do effective research and teaching.

Two other trends of our times, not related particularly to the needs of the handicapped, have also helped me immensely. These are the Chicano Movement and the Women's Movement.

We parents who were left at that fourth meeting in 1968 with only ourselves to fall back on had one other thing in common besides our handicapped children. We were at least 98 percent Chicano. People from New Mexico may not need further explanation, but others will.

My family name, Baca, means that I am probably a descendant or collateral of the explorer Nunez Cabeza de Vaca, who came through the American Southwest in the 1530's and opened the way for Coronado's expedition and later for the Spanish people to colonize New Mexico from Old Mexico. They arrived here a few years before the first English colonists settled in Virginia and Massachusetts. I wasn't taught those facts or other things about my Chicano background as matters of pride when I was a child; rather far from it.

Chicanos were a large majority of the population in Las Cruces, but the establishment and social structure, including the schools, were dominated by Anglos and Anglo values. We Chicano kids learned Spanish at home and then had to learn English when we entered school. We were automatically assigned, from birth, to second-class status. All our conditioning at home and in school was that it was best to be Anglo. Since we weren't Anglos, to get anywhere in life we were going to have to strive to become imitation Anglos. We should not mention even the food we ate at home, we should forget all our customs and language, because all that was bad. We should try to dress, talk, and look like Anglos. Nobody said these things in so many words but they were everywhere in the atmosphere, all the time I was growing up.

It was a losing game. The early Conquistadores had married Indian women, so we Chicanos are marked permanently by our skin color, by our Spanish surnames and often still by accent or poor command of English. In New Mexico, even in recent years, a good many Chicano kids have been put in special education classes for the retarded, when in fact their only problem has been the language barrier.

In school the teachers always asked the Anglo kids the questions because they had the answers and we didn't. If by chance a Chicano kid did something bright in class, everyone was amazed and commented on it. The schools had a rule against our even speaking Spanish anywhere on the school premises and we got in trouble if we forgot it. The rules were supposed to be for our own good but we felt it was to protect the feelings of Anglo kids against the possibility that we might be talking about them.

There were no militant Chicanos then, the word was just slang we used among ourselves. When Anglos wanted to be nice to us, they called us "Spanish-American" and I still don't like that term. If they wanted to put us down, we were "Mexicans" and that is still a fighting word in some parts of New Mexico.

I did get good grades in subjects that interested me but poor grades in classes where I felt the teachers were hostile and indifferent. In my senior year the school administration was excited for awhile because my scores on some tests made me eligible for a college scholarship. There wasn't a thing in my background at that point that would have equipped me emotionally to step up and take that scholarship and the excitement died away fast.

I sometimes wonder how much of my ignorance of the system, when I really needed to know how it worked in order to help my two handicapped children, went back to that aura in the public schools that we Chicanos were second-rate, too dumb to answer questions much less ask them. Certainly the result was profound ignorance about many important things.

Some of the pressures came off accidentally. In 1970 I attended a graduation where the speaker was Dr. Sabine Ulibarri of The University of New Mexico. He raised the question of why people who spoke English with an accent should feel inferior; after all, their accent was proof that they did speak at least two languages. That one remark caused me to drop a whole bunch of inferiority feelings I was hardly aware that I had had.

Today the militant Chicano Movement has produced some changes in the system. Spanish is not merely allowed in New Mexico schools, for example, it is often encouraged. We Esperanza parents, who were mostly Chicano at first, became militant not as part of the Chicano Movement but on behalf of our children. Still, the Chicano Movement has helped to stiffen our spines.

Now we have many Anglo staff members; we serve many Anglo children; and Anglo and Chicano parents serve on our Board of Directors. The full name of our school, after all, is Esperanza Para Nuestros Ninos, which in any language means "hope for our children."

For a long time I thought the Women's Movement was stupid, idiotic, not for me. I didn't take it seriously until my oldest daughter, Denise, got interested in 1973. Denise and I have always been close and now she began bringing home magazines and books and bugging me to pay attention to their message. It was a slow process at first because I just wasn't receptive. Then it began to fall into place.

Chicano women, until the last few years at least, have been much more closely bound than Anglo women into a narrowly defined woman's role. A good Chicano woman traditionally stays home, has kids, caters to all her husband's creature comforts, maybe sews and has a nice garden, thinks of nothing else and, incidentally, gets fat. A skinny woman has had little appeal for Chicano males. The woman who does all that is "happy and content." She also goes to church a lot and my view is that you can see why she would have to.

Even if I had had five normal children, I could not have fit that role. But I was immersed in it from childhood and had no way of visualizing alternatives, even though I was fumbling toward a different lifestyle for myself. I spent a lot of time escaping into books; for years I had four or five books going at once in various parts of the house. Then I began to get involved in Esperanze and I put the books away and began doing things.

Still, I felt guilty because I was not conforming to that narrow, homebound role. When Denise forced me to pay attention to the Women's Movement I began to see myself as an individual with my own needs and to see that it was quite all right if I did get my satisfaction outside the traditional housewife's role.

I feel a lot better now than before I get these things straight. I also think my kids see me more as a person and less as a "mother" and that suits me fine. I still cope with my housework sketchily most of the time, but about once a month I make a real attempt to catch up on it. I am inept in the kitchen but my family does get fed and I have no intention of improving on those skills.

Since Chicano women have been more thoroughly subjugated, their liberation is also more traumatic for Chicano males and Luis has been no exception. It is one thing to seek changes you want, but quite another to have changes in your personal life forced upon you. Luis has had to become much more actively involved with our children in recent years because I have been doing less of those chores and it has not been easy for him.

So our problems are by no means solved. Today I have a few more answers; I am a little more sophisticated; a little less frustrated; a little less angry. But we remain seven people living together in one house, including two retarded children and two normal adolescents with plenty of their own problems. Just getting everyone off in the morning can still turn into a disaster; any mealtime can become a disaster. All this is as difficult for Luis as for me.

When you have normal children, you can look forward to their eventually being on their own. When Cindy and Jason were born, one thing that bothered me most was that I saw them as lifelong obligations. No child should have to live with his parents all his life, and we hope that Cindy and Jason can eventually live in group homes.

Cindy is probably ready for that step now, but in spite of the progress that has been made in the 14 years since she was born, there are still almost no group home facilities for adolescents in our community.

We love our children and want the best for them but we also want a normal life for ourselves. So I live in the hope that we will not have to live this way all the rest of our lives.

Biography

RUBY LUNA was born in La Joya, New Mexico. She is the mother of two handicapped children and of three normal children. She has gained wide recognition for her leadership in the development of parent-controlled, comprehensive, community-based services for the severely handicapped. Since 1971 she has been Director of Esperanza Para Nuestros Ninos School for the developmentally disabled in Albuquerque, New Mexico.

Part III: Instruments of Change

5. The Public

Leopold Lippman

The history of public residential care of mentally handicapped persons in the United States is a chronicle of horrors repeated and rediscovered. Institutions established in the Jacksonian era of the 19th century, as Rothman has noted in *The Discovery of the Asylum*,[1] were designed to offer "moral treatment"; and yet it turned out that they were essentially repressive. Dorothea Lynde Dix,[2] Clifford W. Beers,[3] and Albert Deutsch,[4] in turn, documented the inhumane conditions in mental hospitals which Mary Jane Ward was later to describe fictionally in *The Snake Pit*.[5]

In 1965, Senator Robert F. Kennedy toured Willowbrook State School (as other legislators had toured other state institutions for the mentally retarded in many states), and his shocked reaction gained page one attention; less than seven years later, television newsmen visited the same institution and found the horrors unabated and unrelieved.

Farber has referred to the mentally retarded in sociological terms as a "surplus population," suggesting that they have a marginal role in contemporary society and indeed that their principal contribution may be the very fact that they pose problems and, therefore, stimulate the development of mechanisms to meet the problems.[6] If this analysis is valid, it presents a depressing prospect, because it suggests, as Scott did about blind persons,[7] that service agencies require the continuing dependence of handicapped persons to justify and maintain their own existence. If this is true, nothing less than a total reshaping of society's value structure will make any significant difference in the lives of handicapped persons.

Howard Rusk, in his rehabilitation column in the *New York Times* in 1954,[8] observed that public awareness and acceptance of mental retardation was then where mental illness had been 10 years earlier. In later years, relatives and friends of the mentally ill were to comment wryly—or complain bitterly—that the mentally retarded were getting all the attention and all the public funds. While neither generalization was literally true, the most unfortunate aspect of the statements is the atmosphere of competitiveness they suggest. A casual local survey in the State of Washington in the 1950s showed the relative prevalence of various handicapping conditions among children, and the figures suggested an overwhelming majority were mentally retarded as compared with those having various physical and neurological disabilities. This finding was picked up nationally and has been cited many times in subsequent years, although there was little hard evidence to support the statement. More importantly, the statistical comparison appears to suggest a relative priority of concern among the handicapping conditions, whereas the reality is that various disabilities are associated, often in the same individual and certainly in etiology. The remedies lie not in strict categorization and competitive fund-raising but in cooperative research to find and remove the causes. For the individual the label ("mental retardation" or "cerebral palsy" or "emotional disturbance" or whatever) may lead to inappropriate rather than to effective treatment because each child is unique and is treated more effectively as a person with special needs rather than as a member of a category.

Unless carefully analyzed, the concept of "public opinion" can be quite misleading. Professional workers in public relations recognize that there are many "publics" and that their diverse interests and orientations produce differing attitudes and reactions even to the same set of facts. Edward L. Bernays, perhaps the leading theorist as well as a respected practitioner of public relations, wrote more than a half-century ago, "public opinion is a term describing an ill-defined, mercurial and changeable group of individual judgments. Public opinion is the aggregate result of individual opinions—now uniform, now conflicting—of the men and women who make up society or any group of society."[9] It is helpful, of course, to know that Bernays' own orientation was Freudian; a more sociological approach would focus on the societal forces which lead individuals to think alike, react alike, behave alike. Engels pointed to the economic underpinnings of individual attitudes and behavior.[10] Merton [11] and Lazarsfeld [12] have shown, through field research and theoretical analysis, the source and direction of influences which produce "public opinion" and which modify public attitudes.

What is a "public" reaction? How is it expressed? Even more important, what are its origins, and how can it be redirected?

The public record is full of examples, continuing to the present, of what is usually called "community resistance" to the provision of residential, rehabilitatve and day-care services for retarded children and adults within the neighborhoods of America's cities and towns. The President's Committee on Mental Retardation (PCMR) [13] and the National Association for Retarded Citizens (NARC) [14] have provided continuing documentation of negative community attitudes. Viscardi epitomized the problem in the title of his book, *But Not on Our Block*,[15] and the writer reported this American phenomenon under a similar title in a Dutch magazine.[16]

Yet, when public opinion surveys are conducted, the trend appears to be toward increasing acceptance of handicapped persons. The Gallup Poll, for example, which has been interviewing Americans periodically for 25 years on familiarity with epilepsy, and on willingness to associate with epileptic persons, has reported a substantial trend toward increased acceptance from 1949 to 1974.[17] Clergymen, civic leaders, and public office-holders endorse the provision of community services and the appropriateness of "normalized" treatment of retarded persons; and yet accounts continue to appear in the nation's press under many variants of the headline "Neighbors Oppose Retarded Children." [18] In Seattle in the mid-1950s, the objection to a proposed workshop was that "these grown men with the minds of children will be a menace to our daughters." In other communities in other years, the fear was of an effect on property values, a change in the character of the neighborhood, or simply the statement that "our neighborhood isn't zoned for it." In New York, when the state opened a residential facility for some 200 retarded men in lower Manhattan, the neighbors gave a party to welcome the new facility; it turned out, however, that the previous occupant of the building had been a narcotics addiction center, so that the mood of the neighbors was relief rather than acceptance. In Toronto, however, when the friends of the mentally retarded proposed to establish a residence which would house some 24 retarded persons, the neighbors objected, not because they didn't want the retarded, but because they thought 24 beds were too many. "Why don't you let us help you find individual living arrangements for these people, one or two at a time," they suggested. Allan Roeher cites this as an example of the community being ahead of the official advocates of the retarded, in pressing for genuine normalization rather than the artificial arrangements of a small institution.[19]

The roots of change are difficult to trace; and the deeper one breaks into the topsoil, the more entangled do they appear. In the current era of concern for mentally retarded persons, the rhetorical emphasis is upon "rights" and "normalization" and "deinstitutionalization." Beneath these sloganistic goals, however, are powerful forces in biology and genetics, psychology and sociology, economics and politics.

Change occurs within a social and historical context. Where it may appear that effective advocacy in a state capital has brought about a major legislative or administrative change, the reality may be an event as apparently remote as the development of antibiotics and the consequent lengthening of life expectancy for genetically or perinatally impaired children. Thereupon, the preconceptions concerning retarded persons may be re-examined, the outmoded eugenic concepts rejected, the custodial approach discarded, and the development of community-based, as distinguished from institutional, services encouraged. The sociologist Amitai Etzioni has noted that despite public information campaigns, aggressive law enforcement, engineering redesign and other efforts, traffic deaths continued to go up until the energy crisis forced a lower speed limit, whereupon the highway death rate dropped. He commented: "This is not the only social problem to be drastically affected by factors neither foreseen nor deliberately introduced for the purpose." [20]

This is not to say there is no room for a rational idea, nor for the social compassion which sees value and potential in every human being. Rather, it is to point to the political and economic considerations which trigger social change.

Nevertheless, in the one-generation time span which encompasses modern efforts in the field of mental retardation, there may be discerned three overriding forces: public attitudes, parental involvement, and professional innovation. Among the three it is impossible to draw arrows of causal inference; each has received impetus from, and in turn has stimulated, the other two.

Whatever the manifold factors contributing to the formation of public opinion on mental retardation in recent years, one force appears crucial: the efforts of parents. As narrated in detail by Dorothy Murray,[21] and as summarized by the writer in a review essay on "Community Organization: U.S.A.,"[22] the history of society's perception and treatment of mentally retarded persons since 1950 is the story of the founding, the activities and the impact of the National Association for Retarded Children (now Citizens) and the affiliated state and local associations as well as numerous independent parent organizations throughout the country. In books published almost a decade apart, Alfred Katz told of the early organizational efforts of parents of handicapped children,[23] and Robert Segal traced the political and legislative impact of local and state Associations for Retarded Childred as they had grown into professionalized social agencies.[24]

To begin with, parental attitudes are a crucial element in public attitudes. Goffman has noted that one's self-perception is shaped in part by society's evaluation of the stigmatized individual;[25] but the truth is that it works the other way too. Before becoming the parent of a child called retarded, the typical adult shared the attitudes of the society around him; and in the first half of this century that meant denigration of the handicapped child and his family, a feeling of personal superiority (often with a tinge of moral superiority), and a generalized stance that "it's not my problem." Upon receiving a professional diagnosis that the child is mentally retarded, the parent did not find it easy to unload his preconceptions and the emotional baggage. The scorn, the contempt, the feeling of superiority and the personal unconcern were then transmuted into shame, a sense of disgrace and feelings of guilt.

As many parents felt this way, they kept to themselves, and they kept their retarded children out of the sight of society. The hiding, and the feelings of shame and guilt, reinforced existing attitudes among relatives, friends and neighbors. With such ingredients, it was not possible to bring about social change.

Then, in the 1930s in the States of Washington and Ohio, and subsequently in other parts of the United States, parents began to come together in the interests of their children. (Many of "their children" were, of course, adults, but it was characteristic and significant that the parents considered them, and frequently referred to them, as "children limited" or "forever children.") The earliest organized efforts of the parents related largely to the state institutions, seeking to ameliorate conditions in the way of physical comforts, and also, as time went on, trying to cope with the waiting periods which anguished parents had to suffer after they had made up their minds to "commit."

While the movement toward advocacy had its origins in those first parental efforts, the goals were narrow, limited, and bound by the framework of public (and parental) attitudes. The statewide organization in Washington was typical. From its founding in 1936 until its affiliation with NARC in 1952, this organization conducted its affairs (and occasionally presented itself to the public) under the euphemistic name of Children's Benevolent League. There were three foci of activity: direct services to the mentally retarded children in the state institution, mutual support among the parents, and fund-raising. The direct services usually consisted of gifts, such as draperies and television sets for the institution's numerous "halls," or toys and dolls for those retarded persons who had no parents. The parental mutual support expressed itself informally through the monthly membership meetings and other activities of the League. And the fund-raising—traditionally a "carnival bazaar"—served the dual purpose of soliciting contributions for the gifts to the institution, and giving parent members of the organization an activity which provided an emotional outlet and a sense of "doing something" for their children. While many of the parents appreciated the organization and what it did for them and their children, some also resented it. As one father observed, "My wife and I didn't join this organization; we were forced into it." What he meant was that, active as he was in the group, he had not sought it out as his philanthropic or civic service; rather his participation had been imposed on him by the existence of his retarded child.

When in 1952 the Children's Benevolent League of Washington hired its first (part-time) executive secretary, a man whose prior experience had been in communication and public relations, this was both symptomatic and determinative. The leaders of the organization had decided that the time had arrived for the group to come out of hiding, and for parents of the mentally retarded to confront society at large. Within months, the name of the organization had been changed to Washington Association for Retarded Children, an aggressive public information campaign had been launched, the descriptive brochure "One Out of Fifty" had been completely rewritten and published under the title "She Could be Yours," and a newsletter entitled *HOPE for Retarded Children* (with the HOPE written large) began to appear quarterly and to go to editors, broadcasters and other channels of communication.

These events in the Pacific Northwest did not occur in isolation. They were part of a movement which had become nationwide. There had been local stirrings of parent activity in communities around the country in the immediate post-war years. Then, after a parent spokesman addressed the American Association on Mental Deficiency in 1947, organizing activity moved forward, and by 1950 there came the founding convention of what was to become the National Association for Retarded Citizens.

An early and major activity of NARC was public information. This took many forms: a quarterly national newspaper, *Children Limited;* articles in national magazines; radio and television announcements and special programs; news and feature articles in local newspapers and through the wire services. Parents of retarded children were even writing their personal stories in books. Among the earliest were those by Pearl Buck[26] and by Dale Evans Rogers[27] and NARC quickly capitalized on these publications by promoting them widely. Public service advertisements boldly proclaimed (in the *New York Times*, and later adapted in the *Seattle Times*), "This is the picture of a crippled child," and went on to tell of the invisible handicap, mental retardation. The first National Retarded Children's Week in 1954 was held by NARC not only for fund-raising but for the more basic task of stimulating public awareness. In the same year, Dwight D. Eisenhower was persuaded that mental retardation was a widespread problem, and appropriate for public concern, and he signed the first Presidential Proclamation on the subject. Most of the energy for this spate of public information activity came in those early years of NARC from a small group of volunteers, all of them parents of retarded children: a newspaper man in Connecticut, an advertising executive in New York, a commercial photographer in Pennsylvania, a woman in Minnesota without previous professional communication experience and perhaps two or three others. A pamphlet written by Dan Boyd of New Jersey and published by NARC in those early years described "the three stages in the growth of a parent of a mentally retarded child": (1) Why did this happen to me? (2) What can I do for my child and family? (3) What can we do for others?[28]

It is sociologically significant to note that as NARC was coming into being in the United States, parents were beginning to organize in other countries also. While the emphasis on public information through mass communications was perhaps peculiarly American, the parent movement touched much of the Western world at about the same time.

In recent years, parents have not been alone. As David Rosen observed in his 1974 Presidential Address to the American Association on Mental Deficiency:

"The court cases against institutions, exposes in featured newspaper articles, and television documentaries are much different from those that preceded them years ago. It should be understood that such events are growing, not only as a result of the militancy of parents but of professionals as well. The court cases are different: first, in the attitude in which they are received and, second, in the nature of the recommended solutions.

"Over the past three or four years, I have represented AAMD as an expert witness for the plaintiffs in Alabama, New York and Minnesota. The attitude today of institutional superintendents, and for many in the past, on the matter of updating their programs is healthy. I find no evidence of defensiveness on the part of institutional staff or on the administrative or ward level. They have been candid—they have welcomed help."[29]

The U.S. Department of Health, Education, and Welfare's Assistant Secretary for Human Development, Stanley B. Thomas, Jr., in an address to the United Cerebral Palsy Associations in the Spring of 1974, offered eight predictions of developments affecting handicapped persons in the forthcoming decade. Among these he cited "substantial commitments on the part of federal and state governments for deinstitutionalization," and he added, "These commitments will be wed to reasonably adoptive standards for institutional and community living systems, to manpower training and to the findings of epidemiological research."[30]

If, as must be obvious, public attitudes lag behind informed opinion, it is likewise true that parents and professional workers in the field of mental retardation do not always see the issues (and solutions) similarly. Indeed, there are substantial differences among parents themselves, depending on many factors: the age and degree of handicap of their retarded offspring; the level of understanding and sophistication of the parents; the special economic and other circumstances of the individual family; and so on. Thus, when the official spokesmen and designated leaders of the movement call for "deinstitutionalization" there are some parents and other near friends of the retarded who hold quiet doubts. Elsie Helsel has written, "Parents in some states are already resisting such transfers to nursing homes and small group homes. Many placed their children in institutions because they believed this would guarantee protective care and supervision for life. Parents do not yet feel community residential placements hold such promise of protection—and they are right."[31]

Nevertheless, the trend is inexorable. In 1962, President John F. Kennedy's Panel on Mental Retardation sounded the theme which has increasingly dominated the ensuing years: "Bringing the provision of services as close as possible to the local community is a basic tenet on which the Panel's recommendations rest."[32] Years ago (indeed, in the first edition of this book), Bengt Nirje, then of Sweden, laid out the principle of normalization,[33] which Wolfensberger has more recently elaborated and exemplified.[34]

Whatever the President's Panel found to be wrong with America's institutions for the mentally retarded in 1962 (and the Department of Health, Education, and Welfare with New York's in 1972, and the Department of Justice with Maryland's in 1974), the significant impetus has come from the parents. The bellwether "Right to Education" case came about on the initiative of the Pennsylvania Association for Retarded Children, and indeed PARC was one of the plaintiffs, along with thirteen retarded persons. (It is noteworthy that the Pennsylvania case, in which the federal court affirmed the right of every child to an education appropriate to his needs, had its origins in the concern of the parents for the treatment of their retarded children at one of Pennsylvania's state institutions.)

As Gunnar Dybwad noted,[35] and as Lippman and Goldberg elaborated, the 1950s were the opening years of legislative action, the 1960s were years of executive leadership in government, and administrative implementation, and the 1970s appeared to be the era of litigation, of recourse to the third co-equal branch, the judiciary.[36]

Friendly attorneys have warned the parents and other advocates of the rights of mentally retarded persons that litigation, important and useful a tool as it is, must be used not exclusively but rather as one item in the armamentarium. Thus, in Pennsylvania, as in many other states, recourse to the courts has taken its place among many aspects of social activism. Nevertheless, the principle seems clear. As Joseph T. Weingold put it in the early years of the mental retardation movement: "Although there may be some doubt as to how much we can change our children for the world's sake, there is no doubt how much we must change the world for our children's sake."

The *New York Times* commented on the handing down of the preliminary order by the federal court in the Pennsylvania case:

"The ruling by a three-judge Federal court in Philadelphia that the state of Pennsylvania must provide free public education to all retarded children constitutes a historic step in an area that has suffered from public and professional neglect. . . .

"The education of retarded children is a difficult task, but it is clearly a responsibility to be borne by school and society. . . .

"The court ruling is humane and socially sound. . . ."[37]

While the thinking of the *Times'* editorial writer cannot be taken as a reflection of the current state of "public attitudes," it is perhaps an omen of attitudinal changes to come. In any event, it is clear that such an editorial expression would not have appeared, even in the *Times*, in the earlier years of the parents' movement. Thus the public information efforts, parent advocacy in the legislative corridors and executive offices of government, and the more recent litigatory actions, have had notable cumulative impact.

What does it take to change public opinion? Or, more narrowly, public behavior? David E. Rogers, of the Robert Wood Johnson Foundation, has observed:

"There are no solidly established technics by which broad social change can be produced on purpose in our country. . . . The greatest unmet need is for thoughtful adjustment in the system itself.

". . . In this country, induced change is not a process that can be 'directed' from some remote headquarters. It is one that requires collaboration of many forces."[38]

Some would put their faith in the mass media. It is true, as already indicated, that the use of communications did make a substantial impact in the early years of NARC; but that was an impact of awareness, of replacing a vacuum of ignorance with the substance of information. There is not yet evidence of fundamental changes in public attitudes toward the mentally retarded in the United States in areas of substantive importance, such as acceptance of retarded persons as neighbors or as fellow workers. Lazarsfeld and Merton observe, "Media of mass communication have been effectively used to canalize basic attitudes but there is little evidence of their having served to change these attitudes."[39] More than a century ago, John Stuart Mill put it this way:

"People are more easily induced to do, and do more easily, what they are already used to; but people also learn to do things new to them. Familiarity is a great help; but much dwelling on an idea will make it familiar, even when strange at first."[40]

The experience of Sweden in bringing about a massive change in motorists' driving patterns, as recounted by the writer in *Attitudes Toward the Handicapped: A Comparison Between Europe and the United States*[41] is illuminating. When the Parliament first decided that the nation would switch from left-hand to right-hand driving (Högertrafik), opinion polls showed an overwhelming majority of the people opposed. Even by H-Day, some four years later, 18 percent of the persons interviewed still thought it was a bad idea. Yet, in the early morning hours of Sunday, September 3, 1967, every driver on all of Sweden's roads obeyed the law and made the changeover, and in the ensuing weeks the accident rate was lower than during the same period a year earlier.

The Swedish Högertrafik was a concentrated, intensively staffed, nationwide project, backed by the authority of the law and implemented through engineering, enforcement, information and other measures; and it did, after all, represent a matter of life or death to all the citizens. Still, it might be instructive to ask: would changes in the law in the United States similarly bring about changes in attitude—or at least in behavior? Margaret Crozier of the National Society for Mentally Handicapped Children in England may well have been correct when she suggested that rather than changed attitudes bringing about more appropriate behavior, changes in the objective situation may contribute to modification of attitudes.[42] Certainly the experience of the civil rights movement in the United States showed, during the 1950s and 1960s, that enactment of fair employment practice legislation, while it did not necessarily eliminate prejudice, certainly did reduce overt discrimination.

The question arises: would enactment of changes in the zoning ordinances, or in laws requiring employment of handicapped persons, make a difference in attitudes or behavior of both? The narrow answer would appear to be "No," for, as the *PARC, Mills, Wyatt v. Stickney* and other court cases have demonstrated, the existence of statutes and constitutional mandates does not guarantee obedience even by state government, much less by private individuals. Congressional enactment of Sec. 503 of the Rehabilitation Act of 1973, requiring federal contractors to take affirmative action in the employment of handicapped persons, may provide a practical test in the years immediately ahead. There are some who think the benign quota of handicapped employees, as required in England, is of limited value and in fact may benefit only the most mildly impaired. In a larger sense, however, it must be acknowledged that statutory mandates and proscriptions do establish an atmosphere and a framework within which law-abiding citizens ultimately agree to behave. In the 1973 Rehabilitation Act provision, for example, the most valuable sections may prove to be the one which requires the employer to inform employees of his obligations and the provision calling for reasonable accommodation of job requirements to the limitations of handicapped workers.

Thus it appears that the legislative channel, utilized by the ARC movement since its earliest days, continues to be a useful mechanism. A Connecticut State Representative, cautioning against exclusive reliance on the courts, recently asserted, "The Legislature is generally a more effective place to carry your case."[43] Likewise, the executive branch—expressed in the endorsement of Presidents and Governors, and the active support of federal, state and local commissioners and superintendents—can be a valuable ally. The courts, in a sense, represent but one aspect of the new aggressive advocacy, which takes many forms and enlists many allies. Among these are parents, to be sure, but also attorneys, educators, social workers, health specialists, and other professionals who recognize that their service to mentally retarded persons need not end at the clinic, classroom or office door. Kahn and his associates[44] and McGowan[45] have recently noted the rich variety of modes through which advocacy may express itself.

What this means is that every channel of activity has multiple uses. Litigation, legislation, executive action and public information efforts reverberate and reinforce one another.

If parental action is one root of social change, communication through the major media may well be the transmission trunk. The Scandinavian countries, especially Denmark, have developed a cooperative relationship among the parent organizations, government officials, and the press, which means that a good idea for improving the status of retarded persons find quick responsiveness and dissemination. In the United States, this appears a more limited possibility; first, because there is not the centralized responsibility in government for mental retardation services, and, secondly, because the American press is more variegated than the Danish. Still, public officials as well as representatives of voluntary organizations can develop skill in creating the kind of "news" which attracts media attention. Further, the press has added to its traditional investigatory function the sometime role of advocate so that the print and broadcast media occasionally uncover and push to remedy grossly inappropriate treatment of handicapped and dependent persons.

More basic, perhaps, is the seminal role of rebels in a changing society. Asked what forces brought about the change in the social scene and the growth of permissiveness in The Netherlands during the past decade or so, Mrs. J. van de Wetering-de Rooy, of the Dutch National Center for Mental Health Care, surprisingly gave a large part of the credit to the Provos, the young iconoclasts of the 1960s. By their irreverent behavior, they challenged the soberness and conventionality of Dutch society, and thus contributed to the undermining of previous conformist attitudes on many social issues.[46]

It may be that the youth counterculture in the United States is having a similar effect on long held American ideas, values and habits. It is hard to tell where the anti-war sentiments of the Vietnam era, the Black Power movement, Gay Pride, women's liberation and the jolting effect of Watergate may lead; but cumulatively it seems clear that they have encouraged many Americans to question what previously they took for granted. If the same loosening effect now becomes manifest on prevailing prejudices against mentally retarded and other handicapped persons, it may have a powerful positive impact on public attitudes and social behavior.

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Biography

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6. Public and Professionals

G. Allan Roeher

The potential for a major breakthrough in the organization of human services now appears to be within reach. Never before has so much information been available on social change, partly as a result of recent research in organizational development, social dynamics, conflict theory, group dynamics, advertising, persuasion and communication.

But change of this nature and magnitude is unlikely to come from within professions and agencies now in the field. While most readily conceded that the problem exists and that change and sacrifice are needed, resistance to actual change will be the major obstacle to overcome. Inevitably, each will take the position that it is the others who should change. The primary change agent will ultimately be the citizenry at large.

Even though many citizens still hold ambivalent, unfavorable attitudes towards mentally retarded people, these attitudes are now on the wane. It is being demonstrated that with vigorous action and attitude-shaping, communities will integrate retarded citizens more and more into their mainstream. The extent and speed to which this can be accomplished will depend to a large degree upon demonstration of what can be done. But if concerned citizens are to bring about far-reaching change, they will need extensive technical and professional leadership and guidance. This partnership between citizens and professional workers is illustrated in Canada by the Canadian Association for the Mentally Retarded and the National Institute on Mental Retardation which it sponsors.

The Citizen Action Movement as a Catalyst for Change

Growth in the parent movement in mental retardation in Canada developed slowly between about 1950 and 1960, then accelerated dramatically in the 1960s with a levelling off in the current decade. Since patterns once set tend to run for a long time, the Canadian Association for the Mentally Retarded (CAMR) has attempted to stimulate new patterns of growth to maintain the momentum for change. Recognizing the significance of strength through unity, it has also planned to develop a single thrust for all aspects of the problem—lay and professional, volunteer and staff, public and private. These efforts have blossomed into the creation of about 350 local associations, 10 provincial associations, and a strong federated national body, CAMR itself.

From the outset, CAMR has had several distinct purposes:

1. To be a corporate advocate for rights and interests of retarded people;
2. To serve as a center to which people can turn for information and advice, and as a body which will take action on matters of mutual nationwide concern;
3. To promote research into the causes of retardation, support manpower training, and develop enlightened, practical and economical types of service programs.

The program developed in stages, beginning with the development of specific local services, such as special classrooms and workshops by the local associations, often with little support or even encouragement, and expanding to a wide range of activities as support from public bodies increased.

The second stage evolved from the recognition that such services required a broader technical professional base. In 1965, a nationwide series of demonstration and research projects was launched to train or develop personnel who would be able not only to provide direct services to the retarded, but also to identify and conceptualize service needs and programs of the future and work on the problem of prevention. Though developed by voluntary organizations, these projects, also known as the "Centennial Projects,"[1] drew unprecedented support from federal and provincial government, private corporations and the general public through CAMR's "National Crusade" campaign. These efforts brought some $15 million in new support.[2]

These two phases clearly established the potential for a joint voluntary-government effort in complex long-range developments. They also served as the foundation for the third phase, which evolved from an awareness that existing services were still grossly insufficient to meet the needs of retarded people and were fragmented and unsystematic. Following a series of presentations on comprehensive services by Institute staff at national conferences (1968-69), a nationwide Needs and Resources overview was undertaken. This showed that the cost of meeting the needs of even a small proportion of retarded people by expanding traditional types of services (including institutions, specialized segregated workshops, residencies, camps, etc.) would be prohibitive. In particular, the prevailing pattern of constructing new facilities every time a new group of retarded persons was included in a service seemed to lead to higher costs than the taxpaying public would ultimately tolerate. It was concluded that the emphasis should be on making greater use of existing facilities, and on using generic services which were available to the general public as much as possible.

After extensive study; the National Institute on Mental Retardation proposed a long-term national goal for a more advanced kind of service delivery. This would be:

1. Community or locally based, with services close to handicapped persons in need;
2. Comprehensive in that all levels of need would be met by a wide range of services functioning as a coherent system; and
3. Founded on the principle of "normalization" with its implied integration of the handicapped into society.

In September 1971, CAMR adopted as its major "Plan for the 1970's" the development of comprehensive community services for the developmentally handicapped across Canada. This project, generally called "ComServ", was to take top priority in the concerns of CAMR and of the National Institute on Mental Retardation and is described later in this book. ComServ represents a major focus in the third stage of CAMR's development of services. It is an ambitious plan which will require supreme effort, extensive financial and human resources, and deep commitment. CAMR has recognized that it must assume a major responsibility for the technical aspects and considerable financial obligation.

Cooperation Between Consumer and Professional Bodies

ComServ clearly cannot succeed without active involvement of the citizen action movement. At the same time, the consumer organization needs the back-up of technical and professional resources if it is to be effective.

The National Institute on Mental Retardation (NIMR) was developed to offer this expertise. Under the aegis of the Canadian Association for the Mentally Retarded, it serves as the national technical and professional resource body to governments, institutions of learning, and public and private organizations.

NIMR was developed on the basis of the following concepts and strategies:

1. Changes in attitudes toward research, training and service program activities, and toward retarded people themselves, continue only as long as there are dynamic, well-informed and organized citizen-action groups. Given appropriate leadership and technical-professional back-up, consumer movements have the potential to create major changes in public and professional opinion and behavior.
2. It is essential that a sound and extensive technical foundation evolve in parallel with service program developments and the involvement of the public. Such technical and service developments, combining public and private agency support and blending research, technical-professional and general citizen involvement, will together result in better programs for the client and will accelerate the problem-solving process.
3. A stronger link is needed than has yet existed between theory and practice. The scientist and the teacher still do not communicate effectively with the practitioner; the worker in the field and the parent in the community need ways of chanelling their concerns to the problem solver or researcher.

NIMR is thus experimental, a national effort to bridge the theory-practice gap. It has enabled specialists on the one hand and citizens on the other to bring their respective powers to bear on either local problems or national issues affecting retarded people and those close to them.

The Institute strives continually to increase the quality and quantity of community programs, through collecting, analyzing and converting relevant data into service delivery systems. The function of the Institute is to provide a balance between stimulating research and translating existing knowledge into programs of action. Its challenge is to create change and to effectively deal with it. It sees itself as a problem-solving organization which will carefully assess issues and alternative strategies to make program planning by individuals and groups more effective.

The existence of NIMR will not eliminate service provision problems. The challenges, however, are clearly to reassess and modify service systems, to equip community service systems with trained personnel who will provide direct service and community leadership, and to develop evaluation methods and instruments. The Institute tries to remain flexible and constantly aware of new and effective methods.

The facility is in an academic-research environment, but it is closely linked with the service-delivery system. It attempts not to undertake activities more appropriate to local service agencies, research or training entities. The underlying criteria for selection of problems for study or attention by the Institute is that the issues be national in character and perspective and, where possible, undertaken in collaboration with other organizations and institutions in the country. The intent is to function as the national catalyst, central clearinghouse and the planning entity for the field. Since the Institute is equally interested in theory and practice, it tends to reflect a blend of traditional and innovative attitudes and approaches.

It is located in a new facility constructed through voluntary contributions in the allied institutes' section of a university campus on land leased from York University. It is sponsored by a voluntary organization (the CAMR) but has agreements with the university to collaborate in certain areas of research, teaching, professional appointment and student involvement. Similar arrangements are being evolved with other universities and colleges, in particular the university-affiliated centers on mental retardation in Canada (and some in the United States).

The Institute has formally been in operation for just over four years and is, therefore, still very much in the developmental phase. Professional and public demand for information and guidance in all aspects of mental retardation has been heavy. While responding to this demand, the Institute has also delineated critical priority areas and launched study-action programs in such areas as manpower and training, research and evaluation, program development information resources, legislation, consumer organization, revitalization and international developments.

Since there is no precedent for this sort of body and since it is itself an experimental-demonstration project faced with the challenge of integrating theoretical concepts with actual needs and conditions, it is not rigidly committed to structural formats, operational strategies, or particular sponsorship, organization or jurisdiction. The intent is to remain flexible and responsive to changing needs and to act as a catalyst, so that the repetition of social organizational failures can be minimized or prevented, the progress of one generation can be sustained without loss, and succeeding generations can more successfully build on the past.

The future of NIMR depends in part on its ability to maintain the essential and delicate balance between agencies, people, and institutions with different orientations while still remaining productive. Meanwhile, it brings these groups together and acts as a central technical and program development resource for the nation. It has been the medium through which all interested parties have been able to communicate, cooperatively express leadership and implement large-scale, complex and long-term developments.

References

1. Canada celebrated its 100th Anniversary as a nation in 1967.
2. The population of Canada is approximately 23 million, approximately 10 percent of the United States.

Biography

G. ALLAN ROEHER received his training at the University of British Columbia (B.A., B.S.W.) and New York University (M.A., Ph.D.) in the social sciences and rehabilitation. He is director of the National Institute on Mental Retardation (Canada) and executive vice president of the Canadian Association for the Mentally Retarded.

In previous positions with public and private bodies, his work focussed on long-range planning and innovative program development. He has been closely associated with the field of rehabilitation in

Canada, the United States, and internationally, and serves as a member of the Council of the International League of Societies for the Mentally Handicapped.

7. The News Media

Ann Shearer

Early in 1968, the *Guardian* (one of the three "quality" national daily newspapers in Britain) published an article headed, "Dirty children in a locked room: a mental hospital on a bad day."[1] The description of a children's ward in one of Britain's best known hospitals for the mentally retarded would hardly even shock any more; our senses have become blunted over the years by tales of too few nursing staff trying to cope with a roomful of filthy children who have no stimuli and nothing to play with but their own bodies and excreta. But at the time, it was new.

We were aware that all was not well with our long-stay hospitals; a damning indictment of conditions for elderly people had been published during the previous year.[2] But hospitals for the mentally retarded were places which few outside of the families of those in them and professional people even knew existed. This was indeed my own first visit to such a place. I had only gone there because a letter from a relative of one of the children on the ward to the *Guardian* had described conditions so horrifying that they seemed to demand reporting even if only half as bad as alleged.

The reality was so shocking that the article took some time to publish at all. There had been an appointment with the medical superintendent and the matron, who countered the charges by saying first that they were untrue and then that, if true, they represented an unusual state of affairs, and finally by demanding what else could be expected with such a shortage of staff. There had been basic statistics to collect on the general deprivation of hospitals for the mentally retarded within the National Health Service. There had been hours with the newspaper's lawyer to ensure that the finished article was balanced as fairly as possible between the realities of that one afternoon, the comments of the staff, and the general situation in which Harperbury and other hospitals like it found themselves. The article was not published lightly.

The published reaction to it during the week which followed came from those who had a professional interest in the subject. There was a letter from an official of the National Society for Mentally Handicapped Children urging everyone who had been disturbed by the article to unite: "If all those who were made sick or furiously angry by these revelations were to find their voice, we might effect a change. It's not 'them' who are at fault, it's 'us'." There was a letter from a sociologist expressing astonishment at the description of the ward, although in fact her own study of such places in its sombre documentation of widespread deprivation later gave weight to the groundswell for reform.[3] There were letters from those with relatives in the hospital, either supporting the article or deploring it. There was a letter from a worker in community care pointing out that there were alternatives.[4]

There was also an immediate reaction from the hospital itself. It had not been intentionally that we had taken to task one of the most respected hospitals for the mentally handicapped in the country. There had been an immediate investigation by the hospital's management committee on the day following the article's publication and grave concern was expressed at "this type of irresponsible article and the effect it would have on the parents and relatives of patients and nursing staff." The original visit had been made to the ward "apparently without knowledge or authorization" at a time when that ward was in isolation because of dysentery.

This was the gist of the complaint the hospital presented against the *Guardian* to the Press Council, the body which in Britain was set up to safeguard the ethical standards of newspapers. After some months of correspondence, the two sides in the dispute were, unusually, called to give oral evidence to the Council. Its adjudication finally appeared at the end of the year. "While the subject of the article in the *Guardian*," it found, "is one with which the press has a right to deal, within the discretion of an editor, when the press does deal with a subject of this type, it must be careful to do so with the utmost objectivity and accuracy. The article in the *Guardian* does not conform to those standards. The complaint is therefore upheld."[5] Newspapers are not obliged to publish the findings of the Press Council about themselves but they generally do so in full and this the *Guardian* did. It also (in an act of courage and support for a member of its staff for which I shall always be grateful) took the unprecedented step of republishing the offending article at the same time because it said the Press Council did not specify where the article lacked objectivity or accuracy, because its publication seemed important, because it had taken care to explain the background of staffing difficulties, and because readers might care to form their own judgment.

On the same day, the *Guardian* also published a long description of the pioneering work being done for severely multihandicapped children by one of the voluntary societies. This was not what drew the reader's attention. I had letters and telephone calls supporting me, vilifying me, and asking me to come to see hospitals which were "even worse." The published letters in the *Guardian* over the next three weeks or so were divided in much the same way. Of sixteen published, eight raised the question of inadequate funding for such places. Two reiterated the hospital's view that "gutter press" language, "an attack on people who cannot defend themselves," and the "almost vindictive" printing of an article by a reporter who had entered the hospital "on what amounted to false pretenses" were not only unhelpful but positively harmful: they lowered staff morale and added to the problems of recruitment. Two others attacked this defensiveness. Two spoke of improvements in the hospital since the article was first published; one said the staff had always been kindness itself; one said the *Guardian* should not have republished the article.[6]

Shortly after this, Britain saw the publication of a report which indicated that all was indeed not well in their hospitals for the mentally retarded and this time from an irreproachable source. In 1967 the *News of the World* (a newspaper which claims the world's largest Sunday sales and delights its enormous readership with headlines like "School Girls in Sex Parties Scandal," Deadly Passion for Girl who Called Him Daddy," and "Love on the Set Makes Her a Mum") had published allegations by an anonymous nursing assistant of cruelty to residents in a hospital for the mentally retarded and pilfering of their possessions by staff.[7] It had sent his statement to the Ministry of Health and, as a result, an independent private inquiry was set up to examine the allegations, the state of the hospital, and to make recommendations. The Report of the Enquiry into Ely Hospital, Cardiff, in Wales, was with the Ministry by, probably, mid-1968. It was not, in fact, published until March, 1969, and the contents show clearly enough both why the government was reluctant to go into print and why it showed considerable courage in eventually doing so.[8]

The specific allegations of cruelty were not upheld. Most, but not all, were held to be "due to the persistence of nursing methods which were old-fashioned, untutored, rough, and, on some occasions, lacking in sympathy." But the findings of the report were so damning as to make this almost an irrelevant detail. The committee found overcrowding, low nursing and medical standards, and inadequate management. "The present tripartite administrative structure of the National Health Service has failed, so far as Ely is concerned, to produce a sufficiently integrated service and patterns of care for the mentally subnormal."[9]

This issue was not simply one of a few isolated incidents but of the entire running of a hospital and, by extension, was bound to cast doubts on the adequacy of a whole public service for the mentally retarded. It would be hard to underestimate its effect. The Ely report was the start of a new era in British policy towards the mentally retarded. PEP (post-Ely policy) became a planner's catchword and if we are today a little further towards justice for mentally handicapped people, it is because the *News of the World* took those allegations seriously and because the government published the Committee of Enquiry's findings.

Here then are two immediate lessons on the role of the media in changing our patterns of care for the mentally retarded. The first and obvious role of the media, in this field as in any other, is to provide information. This is the precondition for change; there is no basis for changing anything in our naturally conservative societies unless the electorates have information which persuades them that change is needed. The Harperbury story and the suffering it caused at the time to those concerned in it may seem tame by today's standards. It is hard to believe that such a carefully balanced article would arouse so defensive an outcry among management and staff of any of our institutions for the mentally retarded.

It is hard to imagine that the staff would deny today that such situations happen and indeed are too often typical. That they would still defend themselves by asking what they are expected to do without additional resources is no more than a fair question. The contrast between today's reactions and those of only six years ago shows that the media has done its job. The public has been told what is going on in places which before were closed and the staff knows that the public has been told. A first precondition for change is there.

A second role of the media is to provide a springboard for those who want to see change; a way for them to get in touch with those at the top of our democratic structures who are in a position to make it happen. One way to do this is by providing a forum where the information received can be discussed. The interest aroused by the *Guardian* article the second time around could, no doubt, be at least partly attributed to the added titillation of an adverse Press Council finding and the newspaper's quite unusual step of disagreeing with this in public. Nevertheless, it is worth noting that the debate widened between the first and second reactions from the professionals most concerned to junior members of staff and members of the wider public.

The media can act as rather more direct springboards by giving individuals with an idea to which the media's own audience responds the weight they need to tackle legislators and officialdom. It is a matter of conjecture what would have happened if the nurse at Ely had gone directly to the Ministry of Health with his complaints. To judge by plenty of other examples, though, he would have been referred back to the very same authority which, at the end of the day, was found to be responsible for a situation in which such acts could be alleged. The man was, in fact, told by a senior officer that his life would be made unpleasant if he tried to make an official complaint. The Ely committee itself said, "It is a matter of speculation how long the situation would have persisted had it not been for (the man's) communication to the *News of the World*."[10]

A third way in which the media promotes change is to back it themselves. Clearly, any newspaper will in some sense "back" the articles which appear in it, just as any television station will back their own programs. These would not be set before the reader or viewer if it was not felt (on the subjective judgment of editors and the objective evidence of what interests readers and viewers) that they were worth including. The *Guardian* would not have pursued this story if it had not felt that this was a situation which needed public airing. The *News of the World* would not have put its huge weight behind an anonymous junior employee of a hospital if it had not felt that his allegations needed investigating. But over and above this rule, there is a category of campaigning journalism where the media not only informs and provides a series of springboards for change but where they actively attempt to arouse and mold public opinion along lines which they feel to be right.

Geraldo Rivera's series of scoops during the first two months of 1972 on Willowbrook (the vast institution for mentally retarded persons on Staten Island, New York) must be one of the best examples of this kind of approach in the story of the media and mental retardation.[11] The impetus came from a doctor who had recently been dismissed from the institution but the story very quickly became Rivera's own. The first series of horrific scenes from one of the wards shown on ABC's Eyewitness News attracted some 300 telephone calls of grief and outrage. By the next evening, there had been 700. A week later, Eyewitness News (still running the Willowbrook story) had the highest ratings ever, twice those of its two major competitors put together. Parents held a rally; the inquiry took in state department officials, a congressman, scenes from equally horrifying wards in other New York institutions and community alternatives from New York and California. A news special. "Willowbrook - The Last Great Disgrace," screened about a month after the first news item, was, Rivera says, the highest rated local news special in the history of television.

The drive of the programs was unmistakable: to show just how appalling conditions in Willowbrook could be and to point out that there were alternatives like some of the day-care programs in New York itself and California's community care based on regional centers. Rivera's message was plain: "Change is difficult, but change is necessary. We've got to close that goddamned place down." From the first, the programs pulled no punches; viewers were assailed by shot after shot of naked, deformed bodies, some writhing, some still. There is clearly no impact the written word can make to rival the sight of Willowbrook's worst wards as they were then or of the bundles of clothing hastily dumped into wards at Letchworth Village to impress the visiting congressman.

The whole was unashamedly biased. There was no attempt to show what Willowbrook or the State of New York could provide in the way of better situations. Taken to task for this, Rivera remarks, "The spoken analogy I used to justify my stance was a hypothetical reporter doing a sympathetic report on how nice the hub caps were on Edsels or how well the convicted mass murderer treated his aging mother." Dr. Alan Miller, State Commissioner for Mental Hygiene, in public, at least, supported this stance. "I think it was an honest portrayal of the problems at their worst," he told Rivera. "It may not tell the whole story of the retarded but it does describe, unmistakably, the kind of problems we see. If the public eye leaves Willowbrook and we once again find ourselves trying to go it alone, then I think we struggle to maintain our few gains and we struggle slowly to get ahead."

If the arousal of the public is the criterion of success, Rivera's series is clearly one of the great success stories in the history of the media's relationship with mental retardation. We shall see later what the effect of this enormous rush of public revulsion has been.

I have chosen these three examples of the relationship of the media and the world of retardation deliberately because they are all bad stories. One of the criticisms levelled most often at anyone who meddles in our social ills is that he is interested only in what is wrong about our societies, never in what is right. We are charged with being destructive rather than constructive, of seeing matters in black and white and never in human nature's varying shades of gray. One of the reasons that I have quoted such a tiny number of letters in response to the *Guardian* article at such length is that they seem to convey a fairly representative cross section of views about the media's preoccupation. We are charged very often (as the *Guardian* was then) with sapping morale in situations where it is already dangerously low, with undermining public confidence, and with laying the last straw on the already breaking backs of staff.

There are some fairly straightforward answers to these charges. The only possible response to the traditional question, "Is it in the public interest to publish?", must be, in situations like this, "Would it be in the public interest to keep quiet?" The taxpayer has the right to know how his money is being spent. The citizen of a democratic society has the right and duty to know how his fellow citizens are living. The freedom of the press to put uncomfortable situations before the electorate is an essential element in the assumptions on which our societies are run. And if the media did not fulfill this role, who would? It would be naive to leave it to "those who know best," those most involved. No one, after all, likes to admit that a situation for which he bears any responsibility is a mess. The immediate reaction, as the *Guardian* article shows and experience confirms, is to defend the situation rather than to admit fault. There is often a closing of ranks which at least implies that the public has no right to meddle here; so, in the *Guardian* situation, much was made of my unauthorized entry into the hospital, even though this is a facility towards whose upkeep I contribute as a taxpayer and to which I actually went during visiting hours on the personal invitation of the relative of a patient. And as the Ely story and others like it point out, the chances of an insider exposing a bad situation are extremely slim unless he prepared to court unpopularity at best and dismissal at worst.

The media do not, of course, always act out of crusading moral zeal and this may be one reason why people can find it hard to accept their involvement. What keeps the media going in societies we like to consider well-ordered is what we hope are the extremes on the edge. So bad news sells newspapers and makes people turn on their television sets. The byways of anti-authoritarian feelings or more complex psychology which lead us to this are irrelevant; the fact is there.

Rivera is particularly honest about his own approach to the Willowbrook situation. When it first came to his attention, he reacted with less than the moral outrage he later expressed. "The firing of an idealistic young doctor struggling to improve the plight of his wards seemed a pretty good story but certainly not the giant I was looking for. I asked him to call me back in the morning." Later, it was the "naked children lying in their own shit" who got him his film crew. By the time the first filming and interviews were over, he was convinced this was the giant story he was looking for although he wasn't even then entirely happy that the giant should be riding on the backs of a pack of children living like animals. Those first 300 telephone calls were enough to convince his news director that this was indeed a Giant. Later on, when Rivera's own emotional involvement in the story was growing, it was still the need to make a good story which made him have the cameras track him and the young doctor tearing across the grounds in a sort of back door mercy dash. As he admits, they could probably at this stage have walked calmly through the front door of the place. "But our dash made exciting footage and added an element of drama to what I was consciously structuring as the quest of two young idealists for truth, justice and the American Way."

Clearly, not everyone would use Rivera's tactics and not everyone involved professionally in this kind of story would be motivated by the same impulses. Just as clearly, however, a story can merit the greatest public concern but is not going to get it unless the public can be persuaded to buy the newspaper or switch on the television. Complaints about unnecessary dramatization or black and white interpretations usually come from people so closely involved in a situation that they forget, if they ever knew, how demonstrably hard it is to persuade the public to read or take in very much of what is presented to them.[12] The best hope is to present a few facts simply and with the greatest possible impact, particularly on television, which relies on a series of images which cannot be mulled over later as newspaper articles can.

Bad news, then, is not only justifiable but necessary for a mixture of moral and material reasons and no one, it seems to me, should be unduly squeamish about the marriage if the result is that shortcomings in our social institutions are effectively pointed out to as wide a public as possible.

What of the final charge—that such stories lower morale, sap public confidence, and, in the end, make a bad situation worse? In immediate terms, we can in fact say that in these three cases, at least, they do the very opposite. Straight after the *Guardian* story first appeared, people who knew the hospital well remarked on an improvement which was still sustained nine months later. The conditions shocked one visitor on every visit until the article appeared. "Then the whole scene was changed. No longer faeces on the floor. I've seen it on the table. But every place clean and shining; tables with bowls or vases of flowers; an obvious increased interest on the part of senior staff and an absence of the horrible odour that pervaded the whole place."[13] At Ely, the Report of the Committee of Enquiry brought more, not less, public interest in helping at the hospital, and new wards as well.[14]

At Willowbrook, the immediate effect of Rivera's series (while it was still on) was the restoration of the budget cuts which had played so large a part in bringing its staffing level to something like impossible. There is no doubt, two years after the event, that Willowbrook had improved. There was a lot more energy given to finding work and training for the inhabitants. There was on many wards a staff ratio which made it possible to divide the children cooped within those grim walls into smaller living groups. This is not to say that Willowbrook ever was, or ever will be, anything but an obscenity. It is to say that for the falling numbers who are obliged to live there and the growing numbers who choose to work there, it is better rather than worse than it was.

That the number of children in Willowbrook is falling so sharply (to 4,000 at the beginning of 1974, when it had taken roughly the eight years until 1972 to bring the numbers from 6,400 to 5,300) is in itself significant. Those most involved in the running of the place, from members of its staff to planners and senators in Albany, reckon now that it was Rivera's series which provided the impetus needed to get New York State's plans for the mentally retarded off the ground.

This is not to say that those plans represent the radical change in provisions which reformers might hope for. It must be with something like despair that anyone who wants to see the end of our segregation policies for handicapped people visits the "decent" institutions (patched up old mental hospital wards) or the even more frightening large new institutions which are springing up all over the state to replace the larger old ones.

And here is a very clear limitation on the effectiveness of the media in promoting change. A television series or a newspaper campaign may arouse the concern to bring in the builders and get work started or speeded up but it cannot of itself change the direction of policy. In this case, the policy had been laid down in the mid-1960s.[15] As Rivera himself summed it up, "The expose has created a climate for change but it cannot of itself force change. The burden passes now to the politicians who must respond to the will of the people, legislate the reforms and restructure the way we care for our mentally retarded. Our job is to remind them so that they will continue to care."

When the will of the people can be roughly translated as "do something and quick," this is what the politicians are going to say to the bureaucrats. And what is quicker, in a situation like this, than to blow the dust off existing plans and speed up their use, albeit with some modifications? There is a danger, in situations of public revulsion, of doing the thing that looks like action even though this may be inconsistent with long-term reform. One Albany official, for instance, is convinced that a major effect of the Rivera series was to divert funds into propping up Willowbrook and creating large-scale solutions to the overcrowding; these same funds could have been better, if less obviously, used to create more imaginative alternatives. The problem is understandable. There are, after all, people living in places which, as we have all just seen on television or read in our newspapers, are intolerable. What, in a situation of public outrage, are the politicians to press for and the bureaucrats to do?

The problem is to sustain public interest, not at the level of outrage but at the level of constructive debate which stands a chance of leading to more than panic action reform. Alan Miller raised the importance of sustained interest in his interview with Rivera. "You won't see it all solved in two weeks. I wish you would go back in two weeks and in two weeks and in two weeks because I think that a window on these conditions is necessary. I hope that you would see continued change and that if you didn't see it, that you'd say so."

This, as Rivera says, is a job of the media. It is also, as very many other people say, a job which the media too often fails to do. A quick sensational headline and then out and on to the scandal of popcorn prices: this is a common charge against the media. Certainly Willowbrook itself bears witness enough to the inadequacy of periodic scandal. In 1965, a visibly shaken Robert Kennedy was interviewed after a visit to the place. "In state institutions for the mentally retarded," he said, ". . . particularly at Willowbrook . . . we have a situation that borders on a snake pit . . . The children live in filth, many of our fellow citizens are suffering tremendously because of lack of attention, lack of imagination, lack of adequate manpower. (There is) very little future for . . . children who are in these institutions (which) need tremendous overhauling, and I'm not saying that those who are the attendants or the ones who run the institution are at fault. And I think it's long overdue that something be done about it." Overdue or not, there was little evidence of fast change in the next years. It was thanks to a series of articles in the *Staten Island Press* in 1971 that there was even a small restoration in the budget cuts.

The media, then, tend to hit and run rather than waiting behind to make sure they do everything they can to make the new situation more constructive than the old; they are not good either at making the sort of "reminder" visits which keep the debate going. These are shortcomings which people who work on newspapers and in television will often admit. The reasons may be lack of staff; the staff there tend to be deployed on the immediate and new. But lack of persistence certainly comes in too. It would be naive though to charge this up entirely as a fault. We come back to the essential: the media must sell their product and they must do this by keeping their audiences interested. If, at one moment, the media can be said to lead public opinion, it must always keep a balance between this and following the known preferences of its readers and viewers. There is nothing, as they say, as old as yesterday's news, and yesterday's front page scandal is today's couple of paragraphs at the bottom of an inside left. It is hard fact that readers and viewers, very many of whom turn to their newspaper and television for entertainment anyway, get bored, and need to be presented with something "new."

It is worth noting too that two years after all that emotion and all those phone calls very few volunteers were backing their indignation by making the journey to Staten Island to take the children out or play with them on the wards. No doubt, much of the blame for this must lie with the institution, which took until the end of 1973 even to appoint an organizer of volunteers. But the quality of public involvement needs looking at too. "Why aren't 'They' doing something?" is not the sort of cry that makes for radical change.

Even when public interest is sustained, when the media devote a great deal of time not only to exposing scandals but to encouraging constructive debate, there are clearly many factors which get in the way of change. Peter Townsend, Professor of Sociology at the University of Essex and a close observer of the British post-Ely scene, had this to say two years after the publication of that report. "I would be surprised if there is any period in the history of Britain or any other country, even in the United States during President Kennedy's patronage of the issue, when the needs of the mentally handicapped have attracted greater public attention and sympathy."[18] The then Minister of Health, Richard Crossman, had made improving the situation of mentally handicapped people something of a personal commitment, with tireless visiting of hospitals and well reported press conferences to go with the visits. There had been a succession of revelations about the situations in different hospitals. There had been more column inches and viewing hours devoted to efforts for reform and alternatives to the bleak hospital wards than at any other time. The public was kept reminded not only of what needed to be done but of what was being done and could be expanded. Politicians were very aware of the urgency of reform. And yet, two years post-Ely, there was still no overall plan to solve a situation which, by common consent, was intolerable and had clearly been so for many years.

Townsend sees the essential contradiction of the government's own position as the main cause for delay. It was, on the one hand, trying to find ways to replace the hospitals. "The basic policy will be that never again do we pile up human rejects behind these high walls," Crossman said in September, 1969. Three months earlier, he had pledged more funds to the long-stay hospitals as his priority for the hospital service. Clearly, the government was caught in the same difficult situation as the government in New York after the Rivera exposures. Just as clearly, there are ways of making a swing to care in small communities while alleviating the hospital situation if only these are carefully thought out and reconciled in the context of a clear commitment to the first.

But the commitment never came. When the government's plans were eventually published by its successors, in mid-1971 after some eight drafts, Townsend was not the only person to find it "tragically disappointing in nature and scale," and to warn that it might "result in a pattern of services little better than they are now."[17] The aims of improving the situation of people now in hospitals and creating a thoroughgoing pattern of community care had not been reconciled; the government's plan was thoroughly confused. The principles governing hospital and community-based residences were to be the same. They were to offer the same services to their inhabitants; hospitals were to be phased out; but at the same time, new ones were to be built.[18, 19]

Townsend, writing before this government policy paper was published, cited the very loose nature of central government control over hospitals and the local authorities responsible for community care, the activities of the powerful hospital lobbies and the political powerlessness of the people most concerned—the mentally handicapped themselves—as further explanations for the lack of change. In the three years since the policy paper was published, his analysis has been largely borne out. Hospitals and local authorities have not cooperated as the government hoped they would to create a radically changed pattern for future care, and this is leading to a serious situation. Hospital places are declining faster than others in the community are available. There is, in fact, a steep decline in residential care which the local authorities have not the funds to compensate by providing enough work and support for mentally handicapped people living at home.[20]

It is a situation which, given the differences in funding and responsibility, we can see in many areas of the United States and the point about it on either side of the Atlantic is the same. Even when the media sustain and reflect a very real degree of continuing public concern, there can be no guarantee of the sort of change we want to see. The media, in short, are neither the bogies nor the saviours that they are sometimes believed to be.

The quality of the media's contribution, in fact, is no higher than that of the overall situation in which it operates. We are talking, not of a force which springs fully armed from the printing presses or the cutting room, but of a complex series of interactions between the media, the public, the holders of political power and its executives. If the media are to an extent the leaders of public opinion and so have a powerful part to play in changing our social institutions, they are also mirrors of the situation in which they are operating. They cannot present information which does not exist, any more than they can stimulate debate on subjects on which there is a dearth of constructive ideas. They are also, as we have seen, constrained by their own first need—to sell their product—and the components of that product will vary according to the market they are trying to capture.

Further, when we ask about their contributions to change, we are in a rather uncertain area. What of change in attitudes or measurable change in behavior? "By far the most significant thing to me," Rivera said in his summary of the Willowbrook story, "is that we made people cry." But what, in sheerly realistic terms, are those tears worth today? One summary of work on attitude changes offers the following conclusions: it is possible to change attitudes; in order to produce change, a suggestion for change must be received and accepted; reception and acceptance are more likely where the suggestion meets existing personality needs or drives; the suggestion is more likely to be accepted if it is in harmony with valued group norms and loyalties, the source of the message is perceived as trustworthy or expert, and the message follows certain rules of presentation, organization of content, and so on; suggestion by mass media is more likely to be accepted if accompanied by face-to-face reinforcement than if either is offered alone; change in attitude is more likely to occur if the suggestion is accompanied by change in other factors underlying belief and attitude. It will perhaps come as no surprise after that to learn that it is preceded by a warning that some of these conclusions are questionable and that more work needs to be done.[21]

Once limitations, constraints, and uncharted seas are admitted, however, we can get a clearer idea of the very essential contribution which the media is in fact making to change. It is perhaps time to look again at the spreading of information, at interpretation, and at persuasion.

Adequate information, we have argued, is an essential precondition for change. The media can, first and foremost, spread information about what mental handicap is, and, indeed, what it is not. This is being done through straightforward explanations of handicapping conditions and the place handicapped people may take in society. A recent campaign of the Canadian Association for the Mentally Retarded was based on the theme that handicapped people, given the right support and encouragement, can become contributors to the economy instead of drains on it and this was a message well disseminated by the media. Whether this particular sales pitch is the best one or not, it certainly helped the public understand that mentally handicapped people are only "useless" to the extent that we force them into uselessness by our prejudice.

The media can also, and this is a challenge which we are facing at the moment, provide a platform for mentally handicapped people to explain themselves (who are they?) rather than have other people do this for them all the time. A conference for mentally handicapped people in Britain several years ago merited a good deal of attention in the press; people saw that mentally handicapped people could actually talk and not only that but that many of their perceptions about their own situation were the more painful for being so "normal."[22]

As early as 1968, a Swedish television group included three mentally retarded people in a discussion program about the realities of being handicapped, one of a series of programs devoted to topics of current concern. "The program was the most widely acclaimed in the series; the remarks and the stand of the mentally retarded adults made a deep impression."[23] Chances for mentally handicapped people to explain their own situation on television or on radio are not perhaps as frequent as they should be. The media, perhaps understandably, may feel that the public is not ready for this. Very often, the people who work for the media are not themselves ready to acknowledge that people defined as mentally handicapped have a real voice. But the situation is improving. Just as the public is gradually being informed that these people are not monsters—and we should not underestimate the degree of public ignorance on mental handicap—so they are beginning to have the chance to translate what the experts say about handicapping conditions into a vicarious experience of handicapped people. Barriers to change are being broken down.

The media also provide information about the services which are available for mentally handicapped people. This is clearly of immediate importance to families with a mentally handicapped member who may not know what help they could be getting. The constant appearance of ENCOR workers on television and radio in Nebraska, for instance, has certainly helped that service (described in another part of this book) to reach those it is in business to serve.

More than this, though, the spreading of information about available services is itself a contribution to change. It gives people who know that all is not well with the services they use the necessary information to argue their case for reform in a constructive way. By presenting workers in the field with alternatives to existing conditions, it sparks off in them ideas for changing their own situation. The debate widens; people get in touch with each other. The effects are not easily quantified but the groundswell for change grows, as anyone who has been involved in trying to create it must know. Campaign for the Mentally Handicapped, a numerically small but influential pressure group in Britain, has almost daily evidence of the way this works in terms of interest shown, links established, and enrichment of its own ideas. Those of us who started CMH in 1971 in a London apartment with little expertise and less money know that we would never have gotten where we are today without the media and without the people who contact us because they have heard us on the radio or read about us in the newspapers.

The media also have an important part to play in interpreting facts and events. The very act of processing information must, of course, mean one interpretation of emphasis—of what is important in a mass of material—and we have already seen that a major role of the media is to give platforms to people who have opinions for which they seek public support. Sometimes, however, the media, by their interpretations, can go further than this to support and to foster change at moments when it looks like foundering. In 1972, for instance, five young handicapped men and one of their helpers drowned in Nebraska while on a weekend camping trip from one of ENCOR's community residences. This was a situation which could clearly have led to a public revulsion against the very concept of community care. These five young men, after all, would have been less likely to drown in the state institution. Yet, the press cuttings on this disaster generally show a very reasonable response from newspapers both within the state and outside of it. While some indeed pointed out that the expedition could have been less ambitious, most were prepared to accept the ENCOR leaders' arguments for normal dangers. The whole incident, in fact, went a long way to establishing the importance of the dignity of risk elaborated by Robert Perske, Wolfensberger and others involved.[24]

An incident in Britain underlines this part of the media's role. Shortly after a reconditioning of an old hospital ward to give its residences more privacy and what was described as a "homelike" atmosphere, the building caught fire and 30 severely handicapped men died. Again, the media could have argued for a return to a more custodial type of institutional layout. Instead, there was a general appreciation of what the hospital was trying to do, if misguidedly. One leading article pointed out that many hospital residents should not be there at all. Space was given to letters which argued for small homes in the community instead of upgrading of existing wards.[25]

There is nothing perhaps very dramatic in these examples of the media's contribution to change. But then change, as life itself, is rarely a dramatic affair. It is by an accumulation of such small details that it is produced. Finally, however, a dramatic example. We have seen what happens when the public concern, aroused and even sustained by the media, finds the decision-makers unprepared. When those decision makers are prepared, when the scene has been carefully set, the results can be different.

Nebraska has made a commitment to change from an institution-based to a community-based system of care which is highly unusual in its thoroughness and lack of compromise. This has not happened by accident. The case for change was very carefully prepared by those who wished to see it. It was hardheadedly sold on economic grounds to the state legislators. It was also carefully sold through press conferences and reports and through an impeccably timed ABC program to the electorate. "Out of the Shadows" not only showed the deprivation of the state institution and argued for radical change; it was able to present a coherent plan for that change—not in some distant future, not based on some other state's work, but for tomorrow, based on the work of citizens of the state. The essential information-giving and educative function of the media met with a state of preparedness among the people with ideas and the people with power to legislate for change.

We are back to the central point: the media cannot be of a higher quality than the general situation in which they find themselves. If even undramatic small steps do not seem to be taking place, then it is time we looked at the quality of the information we provide, the relevance of our facts and the standards of our services, rather than chastising the media for lack of sympathy. There is more media space available now than ever before, but the media owe it to no one group in society more than any other. The onus is on those who want change to present a good case. We should not forget the media's final but important contribution to change. Newspapers, radio, and television are fairly shrewd. If they are not interested, it is a pretty safe bet that the public will not be either. This is a sort of quality control we are really rather fortunate to have.

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Biography

ANN SHEARER was born in England in 1943 and took a BA from Cambridge University in economics and history. From 1964-70 she worked with the "Guardian" newspaper, for the last two years as Welfare Correspondent. Since then she has written for different publications on health and social services.

In 1971 she helped start Campaign for the Mentally Handicapped with which she still works in London. During the following year, she spent three months studying services for mentally handicapped people in Canada and the USA. For the past two years she has also been working with l'Arche and has spent a year in one of its French communities.

8. The Legislature

Gary Marbut

A potentially strong and useful component of the American governmental system is the state legislature. Unfortunately, the potential has rarely been reached; the traditional role of the state legislature is reactionary, uninformed, and sometimes weak.

Today, there are 7,561 state legislators in the United States—6,959 of these are men; 602 are women. Thirty-five states have annual legislative meetings. Fifteen states have meetings every two years. All states, except Nebraska, have partisan elections for members of their state legislatures. (For many years, the State of Minnesota also had a nonpartisan legislature but the statutes were changed in 1974.)

Thirty-eight states give state senators four-year terms and 12 states provide for two-year terms. Four states have four-year terms for representatives; 45 states provide two-year terms. Salaries for state legislators, while historically low, have been increasing in recent years. Fifteen states pay state legislators more than $10,000 per year. Twenty states pay legislators in the range from $5,000-$10,000 per year. Fifteen states pay legislators less than $5,000 per year. The state with the lowest legislative pay is New Hampshire which pays its lawmakers at the annual rate of $100. California is the most generous state; legislators there are paid at the annual rate of $26,745. The length of legislative sessions varies from a few weeks in some small states to almost continuous year-long meetings in some large states.

A typical new legislator is elected to his position in the general election in November and is expected to take up his legislative duties in earnest early the following January, which is one reason why new legislators appear naive and inadequately informed. Many states provide orientation training for new legislators but even the best orientation program is poor preparation for the rigors of legislative duty and grossly insufficient background for the legislative decision-making process. For example, a freshman legislator is not likely to know any more about mental retardation than he has read in the books of Pearl Buck.

Legislative turnover is so rapid that sometimes freshmen account for up to 50 to 60 percent of the members; this presents opportunities for leadership for senior legislators and opportunities for influencing by the ever-present lobbies. When pressures of work and time are added to inexperience, leadership and influence, the result has been described by some writers as the "legislative pressure cooker." Examples of the pressure cooker will be found on the following pages.

As late as 35 years ago, state legislatures were perceived as a kind of grass-roots, citizen-participatory check and balance on the powers of state executive departments. It was almost universally true that the executive branch, the governor and his cabinet officers, proposed programs and the legislature reacted; sometimes the reaction was reactionary. Legislatures also tended to respond to private groups. It was common to grant special privileges to large industrial firms, transportation firms, and sometimes labor organizations. During this period in our history, the primary concern of the state legislature was revenue and the allocation of the revenue for state-paid programs and services, such as the construction and maintenance of public roads, public schools, higher education and the so-called custodial institutions. Generations of legislators came and went without providing any innovation or new direction.

States with small populations (under 3 million) have historically relied on agriculture as the occupational source for aspiring legislators. Add a sprinkling of lawyers, an occasional physician, an accountant, a teacher or two, and a few retired businessmen, and you have the formation of a typical legislature during the 1950s and 1960s. With the advent of the one man-one vote rule, and its application to state legislatures in 1965, we began to see a change in the composition of state legislatures. Since that time, there have been more urban-oriented, young, well-educated legislators. The transformation is not complete but it is widely predicted that state legislatures will have an opportunity to evolve into a truly responsive branch of government. It is even hoped by many that the state legislature may actually become a policy-making body, with original ideas and original programs. Observers of the legislative branch, myself included, hope for the day when the legislative branch will initiate programs and the executive branch will have a primary focus of implementation. This goal is in sight, but the process of reaching it will be tortuous.

In the 1960s, for the first time in the history of Montana, a constituency group started speaking effectively and decisively for the interests of the mentally retarded. The center core of this group was the Montana Association for Retarded Citizens, although it was readily joined by a number of other parent and professional organizations. The legislature responded to the advocates in a number of ways.

Until 1967, services available for the mentally retarded citizens of Montana consisted of one state institution at Boulder and a few scattered special education classes in the public schools. The institution at Boulder is located in the Southwestern portion of the state and is 400 miles away from some of the cities and towns it serves. During 1966, a consortium of 17 Eastern Montana counties proposed to the legislature that a decentralized, satellite institution should be constructed at Glendive, Montana to serve the mentally retarded residents of the Eastern portion of the state. This proposal was extremely controversial and drew testimony for and against from far and wide. After a series of extremely close votes, the proposal was approved. A model 32-bed facility was constructed on the outskirts of Glendive, adjoining the municipal golf course. This facility, the Eastmont Training Center, has provided an opportunity for various experimental programs; it is currently being operated as a five-day a week education-training facility for mentally retarded children up to the age of 17.

The last few years have seen an emphasis on the development of community-based programs. This new emphasis, along with greatly increased construction costs, has prevented the authorization of additional decentralized facilities such as Eastmont. Instead, there has been an effort to establish group homes throughout the communities of the state, which has required the cooperation of the executive and legislative branches.

It was discovered that almost all cities and towns in Montana have local zoning ordinances which restricted the better residential districts to single-family residences. These ordinances were interpreted to preclude the establishment of group homes to serve retarded persons, and local attempts to obtain variances proved almost always to be unsuccessful. The legislature was asked to enact a statute defining group homes, serving eight or less mentally retarded persons, as conforming to the single-family residential use of property. The effect of this act was to pull the teeth of local zoning officials who had, up to that point, been unwilling to see any merit to the group home concept. It required three and one-half months of legislative session plus nine months of study and an additional two months of the next legislative session to enact a simple statute. During the process, the proposal was castigated as a vehicle by which neighborhoods would decline, criminal elements would be introduced in every man's home street, and too many cars would use a quiet block. The specters of declining property values, eroded landscaping, and the fears of danger to common citizens were raised.

An official of the State Department of Health appeared before the legislative committee and testified that it was his opinion that group homes would create community health problems, not to mention problems of sanitation. This testimony resulted in an amendment which requires group homes to be licensed by the State Department of Health. Subsequent to the enactment of this anti-zoning statute, there has been an attempt to use the licensing authority of the Department of Health to accomplish exactly what the zoning ordinances accomplished in earlier days—the prohibition of group homes. The legislature, foreseeing this problem, informed the Department of Health that if its regulations are indeed prohibitive to the establishment of group homes, the regulations will be repealed. This contest has not been completely resolved at this writing, although a significant number of group homes have indeed been established.

A potential conflict may be evolving between the operators of group homes and the operators of private nursing homes. There are indications that the nursing home operators perceive group homes as a competitive threat to their industry. This fear may have been the cause of apparent pressure by nursing home operators on officials of the Department of Health in an attempt to make group home licensing as difficult to obtain as possible.

The extent and effectiveness of this influence are unknown at this writing but it is suspected that the legislature may have to contend with this problem as well. The operators of group homes have, in turn, contended that there is no competition between the groups since two different kinds of facilities normally serve two different kinds of clients. Program administrators in other states would do well to heed the Montana experience and be prepared for this kind of developing conflict.

As residential and other community-based services for the mentally retarded are established, increasing numbers of people will seek to use them. In anticipation of this, the Montana Legislature enacted the statute authorizing the provision of "protective services" by the State Department of Social and Rehabilitation Services. While this was being considered, an almost historic battle erupted between two state administrative agencies.

To understand it, the reader must now learn something about the organization of the Montana executive branch. In 1970, Montana voters approved a constitutional amendment which limits the executive branch to 20 departments. Prior to that time, the executive branch had been divided into 161 agencies, boards and bureaus. Pursuant to the constitutional amendment, the executive branch underwent major reorganization which required several major state departments to be involved in services to mentally retarded persons.

The Montana Department of Institutions (MDI) has responsibility for the operation of 11 state institutions (including those for mentally retarded and mentally ill people, the state prison, the juvenile detention facilities), the community mental health programs, and the after-care division which is responsible for the supervision of residents and inmates discharged from the department's institutions.

The Montana Department of Social and Rehabilitation Services (MDSRS) is a combination of the public welfare agency, the vocational rehabilitation division, the developmental disabilities bureau, and agencies serving the aged and youth.

The Montana Department of Health and Environmental Sciences (MDHES) has responsibilities for Medicare and Medicaid certification and licensing as well as the licensing functions previously mentioned. MDHES also has an enlightened and progressive maternal and child health care program and operates an alcohol and drug treatment program within one of the state institutions.

The Office of the Superintendent of Public Instruction (OSPI) is the agency responsible for all school programs except those within the state institutions.

The Montana Department of Labor (MDL) is charged with overseeing state-level fair labor practices and MDL has been allocated a new Montana Human Rights Commission.

During a legislative committee hearing, legislators were treated to the spectacle of officials of the Department of Institutions and the Department of Social and Rehabilitation Services arguing with each other about which would receive authorization to provide the proposed "protective services." MDI contended that it was most logically able to provide such protective services because of the established after-care division with offices and personnel in all of the major communities of the state. MDI believed it was the department with the greatest amount of expertise, with programs for the mentally retarded, and with the state institutions as the training base for personnel to deliver the protective services.

The Department of Social and Rehabilitation Services maintained that it was the community-based department and that MDI should be limited to the walls of the institutions. Further, MDSRS argued that it already had vocational rehabilitation field offices, with counselors capable of serving as the core staff for the developing protective services. Both departments saw the advent of protective services as the opening cannon in a barrage of new facilities, services and programs. Both departments were well aware of the long-range funding implications of these new programs.

As the author of the protective services bill, my initial reaction was that the departmental allocation was of little significance so long as the services did become a reality. However, during the process of the hearings, I became convinced that, in fact, the Department of Institutions was, at that time, a better equipped one to manage and coordinate the proposed services. I became locked in a struggle with the officials of MDSRS, which eventually threatened passage of the bill. Legislative observers recall that this particular disagreement, which took place over nearly two years, was one of the most ferocious in recent memory. My legislation was enacted and approved, but MDSRS finally won the day and became the administering agency for protective services.

It may be that this interesting interdepartmental contest was a factor in attracting the personal attention of the Governor of Montana, Thomas L. Judge. In 1975, his mental retardation and mental health programs are the most progressive and enlightened ever advocated in Montana. Further, the Governor's budget reflect a tremendously enlarged level of funding and an awareness of required improvements in quality and quantity of program staff. At this writing, the plans of Governor Judge, particularly the funding proposals, are running into heavy weather in legislative consideration and hearings. Montana's Legislature has 60 percent freshmen members in 1975, uninitiated in problems affecting mentally retarded people and potential solutions. Among the remaining 40 percent, there is both support for and opposition to new program proposals. For example, one conservative member, who is also a physician, has often expressed grave doubts about the feasibility of community-based programs. Further complications include differences of opinion about the amount and projections of available revenue and the competition for appropriations with higher education, public schools and transportation services. During the last few sessions, the Montana Legislature has shown an uncharacteristically progressive approach to education, training, treatment, and care of mentally retarded individuals. It is my hope that this progressive spirit will continue and that the present "heavy weather" is merely a temporary storm.

Perhaps the most far-reaching recent act of the Montana Legislature is the Montana Developmental Disabilities and Services Facilities Act of 1974. Legislative consideration of this extremely comprehensive and complex bill required nearly two years work. The bill was drafted and redrafted. A series of hearings, at the state capitol and throughout the state, were conducted to determine the readiness of the general population to support the concept of community based services. Support and interest were found to be strong and opposition seemed to be minimal and fragmented. In the closing days of the 1974 session, the bill was approved by the House of Representatives and transmitted to the State Senate. At this time, there was concern about whether or not the Senate would act prior to adjournment. The Senate finally did act, but in doing so attached several significant amendments. The House of Representatives was unwilling to agree to the Senate amendments and, in this situation, the differences were submitted to a conference committee. The conference committee met extensively and ultimately resolved the differences between the two Houses. The bill became law at the end of the session amidst predictions on the one hand that it would prove to be a panacea and on the other that it would prematurely and inadvisedly impose unacceptable services and lead to a public backlash. The act creates a state-level council, joins state and local governments in a cooperative program effort, creates authority for state funding and local taxation, and specifies the services which may be provided. It has been heralded as a model act and is now under consideration in several other states.

The preceding paragraphs may give the reader some perspective on my acute concern about the rapid turnover among legislators, the resulting lack of continuity in the legislature, and the inherent advantage thereby given to the executive branch.

Happily, in Montana, the executive branch perceives its major political objective to be the solving, or at least the amelioration, of the chronic and stubborn institution problems. Governor Judge has stated publicly that if his administration can successfully grapple with the problems of the state's institutions, he will have achieved what no previous Governor was able to do. Montana cal observers believe that the reelectability of or Judge depends largely on the success of mises.

developmental disabilities program was ded during the last biennium at a level of $175,000 per year. The Governor's budget request of the 1975 legislature for the developmental disabilities program was a hefty $7.5 million for the 1976-77 biennium. At this writing, the legislature seems likely to finally approve a compromise appropriation of $5.2 million for the biennium. This vastly increased appropriation can be explained in the following ways:

A. The enactment of the Developmental Disabilities Service and Facilities Act of 1974 presented an appropriate and appealing vehicle for the delivery of community-based services to the mentally retarded and other developmentally disabled persons.

B. The United States Department of Justice has filed a law suit in the Montana Federal District

Court against Montana officials, alleging that the level of care and treatment at the Boulder River School and Hospital is grossly inadequate. The executive branch and the legislative branch have foreseen that this law suit would result in greatly increased expenditures for institutional services. At this time, the resident population of the Boulder River School and Hospital is 399. It seems likely that the legislature will finally act on an appropriation of $19 million for the support of Boulder River School and Hospital for the next biennium. Simple arithmetic will reveal that total program cost will run at the rate of $25,000 per resident per year. At this level of expenditure, it is easy to see the strong pressure for providing alternative community-based services for economic as well as humanitarian reasons. The Montana Legislature has agonized over the future of the Boulder River School and Hospital. The Governor's Mental Health Advisory Council, which has responsibilities in the field of mental retardation as well as in the field of mental health, and of which I am the chairman, has studied this question and has projected a reduction in resident population from the present 399 to 200 by the end of 1977. It must be realized that the easy reductions have already been made. Three years ago, the institution at Boulder had over 1,000 residents. At present, the residents are severely and profoundly retarded persons and in many cases multiply handicapped. These residents represent a more difficult challenge for community placement than did their moderately retarded predecessors.

C. The public school system in Montana has conducted special education classes in some cities for as long as 13 years. Students who entered special education at the age of six years are now being graduated from high school special education programs. In some cases these programs have prepared students for occupational placement and independent community life. In other cases there is an obvious need for community-based work-station and work-shop programs along with the necessary supporting continuum of services. In short, the responsibility for education of special students is now being placed at the door of city hall.

D. Mentally retarded and other developmentally disabled persons, who have not received institutional or educational services, are becoming aware of the availability of services through the parent association and the efforts of professional organizations. These persons are being given the opportunity to attend "catch-up" educational programs to prepare them for community life. In Montana, as is the case with many other Western and rural states, there is a heavy dependency upon the family home as a major resource for care and treatment of the mentally retarded person. This reliance has resulted in a degree of isolation and is typically broken down only at the time there is a threat to the health of one or both parents, at which time community resources are sought as alternatives. The publicity about the availability of community-based programs is generating interest and awareness on the part of parents who might otherwise keep their children at home indefinitely.

E. The State of Montana, particularly the Western portion of the state, is attracting a substantial population growth. This migration tends to be from large, urban states, where programs for the mentally retarded have been in effect for many years. Consequently, we find families with retarded children moving to Montana, expecting to find services and when they do not, these families become strong advocates for the establishment of advanced programs.

The Montana Legislature has responded to the pressures indicated in the preceding paragraphs by authorizing the $5.2 million appropriation referred to earlier. The reader of this chapter may have as his frame of reference expenditures in a large state which will make these few million dollars seem insignificant. It is my hope that the reader's attention will be caught by the contrast between $350,000 in the present biennium and the $5.2 million in the next biennium. Added to the $5.2 million will be federal matching funds and some support from local (county) taxing authorities.

In Montana, the question of financial charges for room and board received at the state's institutions is controversial and complex. These charges, known locally as "reimbursements", have traditionally provided substantial revenue to the state general fund and have tended to offset a portion of the cost of operation of the institution. During several legislative sessions, I have attempted to obtain legislation to eliminate, or at least limit, the extent of these reimbursements, which are assessed and collected by the reimbursement division of the Department of Institutions.

Eventually, at my request, the legislature enacted a statute which does indeed limit the authority of the reimbursement division. The statute recites that in the case of a resident over the age of 18 years, the reimbursement division may not assess or collect charges from parents or other responsible persons. In the case of residents under the age of 18, the division may assess charges against parents or other responsible persons if those charges do not exceed the cost of supporting a normal child of the same age in his own home. My rationale for requesting the enactment of this statute was that to do otherwise would be to discriminate against the parents of retarded children; parents expect children, all children, to be at least mostly emancipated by age 18. To ask for a lifetime of reimbursement charges in the case of retarded children, while not similarly penalizing the parents of normal children, is to discriminate. In spite of this seemingly simple and lucid rationale, this legislator experienced the aggravation of tenacious and successful opposition to this proposal by the officials of the reimbursement division over a period of many years. Ironically, the former administrator of the reimbursement division was convicted in state district court on criminal charges of embezzlement of reimbursement funds. The amount embezzled was alleged to have been almost equal to a one year fiscal impact of the statute described in this paragraph. It may be that this criminal conviction played a part in the successful enactment of authority limitation.

The reimbursement problem has been solved, only insofar as the parents and relatives of handicapped children are concerned; it is still possible to assess reimbursement charges against residents *themselves*. In cases where residents have their own income, or their own assets, the division can and does collect from these residents. It is common practice today for the division to "draw down" the individual bank accounts of individual residents to the level of $25 as a means of collecting reimbursement payments. The recent decision in the case of *Souder v. Brennan* requires that state institutions pay residents if these residents perform work within the institutions. For the first time in Montana, many residents now have their own earned income. The question is, should the state, acting through the reimbursement division, have the authority to take away with one hand that which was given to the residents with the other hand for work performed? A major fiscal impact in this area is the receipt of medicare and medicaid funds along with other third party reimbursements, and the requirement of these funding sources that no discrimination between "charged" versus "free" services be permitted. The readers of this chapter may be interested in investigating similar questions in their own states, since only a few states have undertaken to clarify administrative practice in this area.

A potentially explosive situation presently exists within the Boulder River School and Hospital. It has been reported that certain resident deaths have occurred as a result of alleged withholding of certain medical treatment or procedures. A former superintendent at Boulder attempted to draft rules and regulations which would specify the process by which decisions would be made relative to the provision, or nonprovision, of medical treatment in particular cases. In reality, the superintendent was attempting to limit the authority of the medical personnel and to impose a degree of prescribed procedure into the medical decisions. Unfortunately, the public perception of the former superintendent's efforts was that he was on a crusade to permit the withdrawal of life-sustaining, or life-preserving medical treatment. In these circumstances, a storm of protest arose and the efforts to reduce these extremely sensitive questions to written policy were abandoned. This abandonment has been perceived by some as extending carte blanche authority to medical personnel to make unilateral decisions, regardless of the gravity of the effect on human life. Reported developments in a recent case are so bizarre, and seem so startling, that there is almost certain to be an exposure of the practices and perhaps additional remedies may be sought. The paragraph should not be interpreted as a condemnation of Montana institutions to the exclusion of raising similar questions about institutions in other states; it is my belief that these issues probably exist in many states, but are, for the most part, carefully concealed from public view.

Closely akin to the "right to life after birth" issue in the preceding paragraph is the issue of the use of human subjects for experimental research. At one time, it was believed that the recently enacted federal law would provide adequate protection and guidelines. It is now believed by many that it will be necessary to have state-by-state legislation to adequately define the pivotal concepts of "informed consent" and "direct therapeutic benefit." If informed consent can be properly defined, and if it can be applied to a particular individual, and if that individual does give informed consent, then I have no concern. The problem arises in cases where informed consent cannot be obtained, and what procedure may be substituted for informed consent. It is the view of many in the Montana Legislature that the only acceptable substitute for informed consent is an appropriate court procedure which will satisfy due process requirements as well as determine something about the substantive merits of the experimentation proposals. Equally complex, and equally significant, is the question of whether or not the subject of a proposed research experiment should expect to receive some direct therapeutic benefit. Legal rights authorities and research authorities are at loggerheads over these questions. It is my conviction that the state legislative process is uniquely qualified to evaluate and resolve the existing disparate views.

Early on, special education was seen as a panacea for the problems of mildly and moderately retarded children. Organizations such as the Education Commission of the States, based in Denver, with its handicapped children's project and the National Council for Exceptional Children were pioneers in efforts to suggest and obtain enabling legislation to provide special education. Montana was among the states which enacted permissive, but not mandatory, special education legislation in the early 1960s.

In spite of the permissive legislation, coupled with the incentive of triple state education payments, local school districts typically resisted, and for the most part, did not establish special education classes. There were notable exceptions to this general pattern of resistance. The exceptions produced notable special education programs in two or three major Montana cities. After a few years, the legislature amended the special education act to make special education a mandatory requirement in school districts where at first ten, and later seven, appropriate special education students were identified and in residence. The result of this development was that most of the cities in Montana soon established, and improved, special education programs, but the crying need continued to be in the rural areas where seven or ten special education students could not be found in individual school districts. Also, the law did not provide how many special education classes should be established and maintained; it was sufficient to satisfy the law if the school district established a single class and left other students without educational programs.

In efforts to remedy these problems, the Montana Legislature in 1973 took under consideration three major legislative proposals:

A. We introduced the Council for Exceptional Children Model Act, a complete and thorough mandatory special education proposal, modified only slightly to suit the peculiarities of the Montana law.

B. We introduced a much simpler, amendatory act, to bring existing statutes into conformity with broad definitions of student eligibility, together with a requirement that special education services shall be available to every Montana child no later than January 1, 1979.

C. We introduced a bill to repeal the financial incentive (the triple state education payment) and to replace that plan with a system of "excess costs." The legislature had been told that certain school districts had used state education money, intended for special education, for other, non-intended purposes. The excess costs formula was conceived to correct this practice, to more equitably distribute available revenues, and to spread these revenues over a greater number of special education students as well as to build into the system a higher degree of accountability. It was also believed that if the federal government should undertake major funding of special education programs, it would be on the basis of excess costs; so it was our intention to prepare the Montana system in a way which would maximize the receipt of federal funding.

The three proposals recited above were referred to the House of Representatives' Committee on Education chaired by Representative Jack Gunderson of Great Falls. In cooperation with a ranking minority member, Representative William S. Warfield IV of Livingston, Chairman Gunderson undertook a year-long intensive evaluation of special education services and of the proposals to improve the services. An interim joint committee of the House and Senate, chaired by Senator Pat Gilfeather of Great Falls, undertook an intensive investigation into the alternatives of special education financing. The result of these committee deliberations was a recommendation that the legislative proposals (B and C described above) be enacted.

What followed was a series of legislative hearings on the substantive merits of special education, of educational philosophy and of fiscal policies. It was of major concern to the legislature to learn what impact these proposals would have on established general education. By this time, educators were largely, although not completely, in support of the expansion of special education and of the mandatory requirement and of the need for fiscal reform. In opposition to the proposals, we found some school administrators, some school board members, and a conglomeration of concerned and aroused taxpaying citizenry. The rules of the Montana Legislature provide that any bill with a fiscal impact must carry with it a "fiscal note" which is prepared by the governor's budget office. The fiscal note is a device intended to define for the legislature the extent of the fiscal impact of a particular proposal. In the case of the special education proposals, fiscal forecasting was extremely difficult. We had fiscal notes, revised fiscal notes, and revisions of revised fiscal notes, running from a few million dollars to many millions of dollars per year.

Almost unnoticed in the confusion of testimony presented to the legislative committees was the proposed final implementation date of January 1, 1979. As chief sponsor of the legislation, it was my doubtful privilege to negotiate a final implementation date which was realistic, achievable, and acceptable to the education agency. Our negotiations took place over a period of several weeks, during which dates as early as 1976 and as late as 1981 were discussed. 1979 was unacceptable to me, but it represented the best available concession from the education agency and the local school officials. At the time of final enactment of the package of legislation in 1974, I made a final plea to the legislature to change the final effective date back to 1977 or 1978. That plea did not prevail in the customary pressure of 11th hour legislative seesaw bargaining.

Since the day of enactment, I have watched with interest the preparation of the school system for the advent of complete and final implementation for all children. Notable progress has been made, but there are areas and issues which have developed much more slowly than anticipated. One of these is the development of a pool of suitably trained teachers. In practice, the education agency has elected to certify a number of teachers for special education classes who have not had specialized training, upon the condition that specialized training would be obtained within a specified period of time. The result of this practice has been to establish a large pool of teachers, but they are a large pool of teachers who have yet to earn special education credentials. For this and other reasons, I am of the opinion that the 1979 date may not be as unfair and unrealistic as it was believed to be a year ago. The current experiences of some other states, involving difficulties of implementation of mandatory special education, lead me to believe that Montana will be well served if, in fact, our mandatory special education act is voluntarily implemented with sufficient time for full and complete implementation. If this turns out to be true, we may have the reality of special education earlier than if Montana had to spend the year or two in court in an implementation effort.

In February, 1974, I had the privilege of escorting a special guest to a session of the Montana Legislature. The guest was Beverly A. Rowan, then a Professor of Law at the University of Miami, Florida, and later to become Director of Advocacy at the Kennedy Foundation in Washington, D.C. One of the bills under consideration on that day was a proposal to establish in Montana a state commission on human rights. Ms. Rowan, an authority on human rights legislation, suggested the inclusion of persons with mental and physical handicaps in the various nondiscriminatory sections of the bill. Acting on Ms. Rowan's recommendations, I was able to have the bill referred to the Judiciary Committee and subsequently to a subcommittee of which I was senior member. With Ms. Rowan's very detailed draft amendments in hand, I was able to convince the subcommittee that every one of the 19 sections of the bill should include provisions for the mentally and physically handicapped. The bill was later enacted, with the amendments intact, and the Montana Human Rights Commission has since been established. The new full-time attorney for the Human Rights Commission has informed me that the area of the human rights for mentally and physically handicapped people is more challenging and has greater change potential than any other area of responsibility given to his agency.

A new section to the Human Rights Commission Act, in which discrimination against mentally and physically handicapped people is prohibited in the matter of credit transactions, has been added by the 1975 Montana Legislative session.

The citizens of Montana have the impression that the Montana Legislature, in general, and myself in particular, have been responsible for notable and far-reaching statutory gains which will improve the lives of Montanans who are mentally retarded. While I am in agreement with this impression, I have two reservations:

A. The advances, the gains, and the changes represent only a part of the improvements which are available and which should be achieved. To paraphrase the Governor of the State of California, "I came with modest expectations; they were fulfilled."

B. The Montana legislative accomplishments over the last several years would not have been possible without the loyal informed, enlightened, and effective support of a group of outstanding legislators and without the help of a dedicated, able, and sometimes brilliant professional staff. It has been only by accident that my roll has been such a visible one in Montana. I wish there were some way to distribute the credit among those legislators who have worked very hard and deserve credit for their efforts. Included in this group are two especially talented Montana lady legislators, Representative Dorothy Bradley of Bozeman and Representative Gail Stoltz of Valier.

As a micro-subject of the study of a state legislative system and how the system reacts to the problems of mental retardation, Montana provides an excellent example. It has been my intention, in this chapter, to relate the Montana experience in such terms that readers will be able to translate the accomplishments and opportunities I have described in their own states, with potential replication and improvement of our track record.

It is my solid conviction that the road to future improvement in the lives of mentally retarded persons passes through the several state capitols. I believe that legislative action, legislative reform, legislative appropriation, and legislative awareness are the most promising available avenues to lasting beneficial change. Advocates for mentally retarded citizens exist presently in every state legislature. Properly motivated, properly supplied with information and professional resources, these legislative advocates can accomplish for mentally retarded people in a very few years what might otherwise take forever.

Biography

GARY R. MARBUT is a resident of Missoula, Montana, where he and his brother own and operate a cattle ranch and land development business. He presently serves as Chairman of the Governor's Mental Health Advisory Council, after having recently completed nearly ten years service as a member of the Montana Legislature. The father of a mentally retarded son, Mr. Marbut received his education at the University of Denver and at the University of Montana.

9. The Executive

Burton Blatt

The contents of this chapter derive from activities during my years as administrator in government and academe. Essentially, the plan is to present a personal analysis of this crazy business we call "mental retardation." It may strike some readers that this chapter's organization is the reflection more of idiosyncratic conceptualizations than of logical processes. I must admit that I believe that, in this crazy business, one fights general craziness with any resources at one's command, even those which are paradoxical or illogical. In this regard, my long suit has always been independence. Some people may define such resistance as hostility, a transference mechanism, or whatever; I choose to interpret their definitions as other examples of this crazy business. In a world of continuous war on peace, where people incarcerate, and even kill each other, because of labels ascribed to or withdrawn from human beings, should anyone be surprised to read here that I call this business crazy, that there may be some who will think me crazy for it, and that I would find such reactions to be but additional illustrations of the craziness in our field?

Dreams and Means

One should start at the beginning, and the beginning for me must include the language of theory, laws, beliefs, and prejudice—statements of principles-goals and their pragmatic translations. So, first the principles and goals and, secondly, with a degree of diffidence, how I have interpreted them.

Ideas

It seems entirely reasonable to suggest that goals represent important ideas to be achieved during some future period. Stated another way, I envision the term "goal" as including to some degree, and embodying but not encapsulating, such other terms as "objectives," "hypotheses," "dreams," and—most of all—"ideas." At least while I write this chapter, I have persuaded myself that there are compelling ideas that seek expression, that there are people in this field who agree and disagree with these ideas, that one way of gaining a perspective on the "mental retardation" business is to evaluate those ideas.

The ideas are everywhere—in the literature, at the conventions, in the academy, in the aide. Typically, we express them as researchable hypotheses or as pragmatic goals. Typically, we find them substantively discussed: (1) as the educability hypothesis, or the nature-nurture controversy, or the human potential movement; (2) in agreement that human beings are entitled to fundamental services and opportunities, or that there should be options available to all people; (3) in the belief that the state has certain responsibilities to the people, and the people have certain rights; (4) or as more specific goals, such as the recently publicized White House hope to reduce the incidence of mental retardation by one-half by the year 2000; (5) or as very general goals, such as to guarantee each person the right to be born healthy, the right to habilitation, the right to the least restrictive placement, the right to an appropriate education, or the right to equal protection and due process under the law.

There are goals, objectives, dreams, and hypotheses; but, at the beginning, there must be ideas. Unfortunately, one reason why many ideas are timeless and persistent, yet feeble, is that they haven't fully existed in reality; we don't feel compelled to implement them. And, one reason why we aren't so compelled is that ideas, like people, are themselves mixtures of weakness and strength—which itself may be an important idea. Possibly, such mixtures are inevitable, the products of dissonance between intent and practice, noble hope and dismal realization, and shared bitterness. The lesson is plain. Be humble or one has very little to rely upon.

The following are some ideas that I feel are now in the air, not always because they are loud or striking but, rather, because they are fundamental and each possesses the sound of truth:

The idea that each human being has unique value. Not only is each person educable, not only is capability a function of practice and training, motivation, and expectations, not only must all developmental programs be individualized, but so must one's life objectives. This is by way of saying that, although we believe that people can change, an individual's value as a human being isn't bound to his educability but to the intrinsic and inalienable right to be respected—because he is a human being, if for no other reason.

The idea that children represent our great hope to improve society. An individual is born and he dies, and during the interim, he struggles to realize his gifts, while the group—the government, the bureaucracy, what we call society—seeks to trap him, tame him, certainly standardize him. But, sometimes for good and sometimes for bad, there have always been people who would not be molded. They cause us problems; yet, they are our major investment for the future. The dilemma has always been to know who should be molded and controlled and who should be as free as the wind, who is dangerous and who is our prophet. And, so, we encourage freedom and individuality, while we weed out those who appear to be dangerous and maladaptive, while we pray that serious blunders have not been perpetrated in the name of society. And children must always exemplify humanity's universal continuing enthusiasm for a better future; therefore, if we fail with them we fail with everything.

The idea of the creative person. Each human being has a will to live, but also a dream to express himself, to realize his individuality in unique ways. Someone once said that living well is the best revenge. And, I truly believe, if we can agree that "living well" means living on one's unique manner, that living well is the only way. It's not enough to live, to exist, to be; all people seek to unfold, work to create something, and struggle for a principle or some different future.

The idea of freedom. A jaundiced assessment of our culture is that we revere life but disdain freedom. In our zeal to protect the weak, the aged, the so-called handicapped, and the ugly, we segregate and separate and stigmatize and make pariahs out of legions of people. We build industries to incarcerate—out of sight and out of mind—the blind and the retarded and so not only do we accomplish little to help them "see" and understand us but we preclude any possibility that we—the sighted, the brilliant, even the humanitarian—will "see" and understand them. Where is the liberty that our fathers wrote of in our declarations and constitutions? Where is the liberty that children every school morning across America claim their country guarantees for all of its citizens? Where can we find total implementation of the principle that a human being is entitled to freedom under the law?

All Ideas Have Histories

Each of these ideas has a history, long and bloodied. Wars were fought and lives were lost because of them; the idea that all people are entitled to freedom under a just law is one that has turned red the soil of most lands. So, today, these ideas struggle against other powerful ideologies, moving ahead, then falling back, in favor during one generation and out of favor in another. Today, at this very moment, it is no different, except for the difference in time and perspective. However, ideas dealing with freedom, individuality, human values and human resources continue to intrude into public consciousness, crying for legitimacy and support.

I have learned that one way to at least partly understand what our values are is to read the papers and listen to the public communicators. As the saying goes, look it up in the newspaper; everything begins with the birth announcement and ends with the obituary. Unfortunately, people may draw wrong conclusions from discrete facts; hence, this attempt to relate "word" facts with "deed" facts. It's necessary; for as all ideas have histories, so do all people. But some leaders tend to think they don't, that each day is a clean slate in a new world.

The following items have appeared in our New York State newspapers in recent months:

> "A bill passed last month by the state legislature and sent to the governor for signature changes the names of all department facilities for the mentally retarded from. 'State School' to 'Developmental Center' . . ."[1]

No longer will we have to contend with the Syracuse State School, the Willowbrook State School, the Letchworth State School, the Wassaic State School, or the Newark State School. Rather, there is a new model; new progressives and humanitarians appear to be in control. We now have the Willowbrook Developmental Center and the Letchworth Developmental Center. We change the names and, as if by magic alone, things are expected to get better.

> "The playground of the Syracuse Developmental Center is going to be

> remodeled stressing safety and more creature comforts. Protruding bricks removed from all play areas and smooth epoxy applied to the sides of the slide to prevent abrasions are just two of the improvements to be made according to Al Clinton, assistant business officer of the Center. Improvements are being made to provide more safety to the retarded children that the Center serves"[2]

Some who read this announcement in our local paper remember that the Syracuse Developmental Center (formerly Syracuse State School) was once the oldest unremodeled and unchanged state school for the mentally retarded in North America and, just a year or two ago, it was torn down and rebuilt at an expenditure of approximately $25 million. The aforementioned playground, constructed at a cost of several hundred thousand dollars, received more than one national award for its innovativeness. Unfortunately, children couldn't play in this playground without submitting themselves to unusual physical dangers. Essentially, this award-winning playground built by the New York State Department of Mental Hygiene was, and probably still is, "unplayable."

> "A State Comptroller's investigation of Matteawan State Hospital in Beacon, N.Y. has uncovered a pattern of fraudulent transactions and irregularities, including the bilking of inmates through doctored commissary records.
>
> "A still-confidential audit report obtained by the *New York Times* showed that, in one recent six-month period, inmates were overcharged $12,235 in commissary purchases.
>
> In some of these cases, the report said, inmates 'appear to have been charged for non-existent items' "[3]

Mental health and mental retardation are big business. In each state, not only is the state itself the "biggest" purchaser of new construction, but the state is in the position to offer millions of dollars in food, linen, garbage, you name it, contracts. Further, state employees handle transactions involving millions upon millions of dollars, oftentimes "on behalf" of incompetent, or presumably incompetent, inmates. So, the *New York Times* reports that "A Matteawan audit shows inmates were defrauded." What else is new?

> "It was a scientific experiment. For 30 years Federal health offices allowed 400 poor Black men known to have syphilis to go untreated despite the discovery that penicillin could cure their devastating disease . . .
>
> "Eight years ago, as part of a study of immunity to cancer, a leading New York cancer specialist injected live tumor cells into elderly clinically ill patients without ever telling them in plain English what they were being given and why . . .
>
> "Nearly 400 poor women—most of them Mexican-Americans who had already borne many children and had come to a San Antonio Family Planning Clinic for contraception—were enrolled in a study a few years ago to determine whether oral contraceptives did in fact cause psychological changes. All of the women were given identical-looking drugs, most of them active contraceptive agents. But 76 women received a 'dummy' or placebo drug. Seven pregnancies occurred before this study was ended, six of them in the placebo group.
>
> "In 1967, coercion was charged in conjunction with a study in which live hepatitis virus was injected into mentally retarded children at Willowbrook State Hospital on Staten Island . . ."[4]

Probably also reflecting its revulsion from the above kinds of human treatment, all of it despicable, probably some of it criminal, the *New York Times* headlined the above article by Jane Brody, "All in the Name of Science." Yet, let's now read a portion of a recent editorial in that same newspaper, reputed to be, and deservedly, the paper of record. Let's read the view of a newspaper that is not too immodest to claim that it published "All the News That's Fit to Print."

> "A wasteful dispute has long been seething between civil libertarians and elements of the psychiatric profession. The issue, in effect, is whether the mentally ill should ever be hospitalized against their will or must at all times be left to their own resources as a recognition of their rights as free citizens . . .
>
> "What are needed are open halfway communities, preferably located in rural areas, where the less afflicted can work at farming or crafts . . ."[5]

Why did the *New York Times* print this lead editorial, titled "Civil Liberties for What?"

With the world at war, Watergates, impeachments, runaway inflations, pollution, crime, Henry Aaron and the new baseball season, with a whole world of problems and happy and sad events to choose from, why did the *New York Times* feel compelled to report to the world that mental patients really need communities away from typical society, preferably located in the country? Apparently, even the *New York Times* can be misled, possibly by a few influential colleagues or, just as possibly, by a great many Mr. and Mrs. Citizens who plunk down their twenty cents on weekdays and one dollar bills on Sundays for the privilege of not only reading the paper of record but giving it advice.

Apparently, the people in New York City have "had it." So too, apparently, has the New York State Department of Mental Hygiene. For, in an April 28, 1974, front page article, also in the *New York Times*, it was reported that the ". . . Department of Mental Hygiene, in a private memorandum and directive, has made a major change in its policy by telling its hospitals that 'we should not take the initiative in discharging the patient to the community.'"[5] Why, after the scandals of Willowbrook and Letchworth, the reports of joint commissions, with a new morality and in a supposed era of concern, does the *New York Times* ask us to slow down, if not apply the brakes? Why does it appear that the State Department of Mental Hygiene is doing one of its familiar herky-jerky about-face dances, tiptoeing in a 180 degree turn, skimming over the issues and principles that honest people would not ignore? Well, the Department of Mental Hygiene not only has "had it," but was "had"—by the "anarchists," the too-liberal psychiatrists, the reformists.

When they were persuaded to evacuate some of their more embarassing units, they were not told that many people would be unimpressed with the idea that mental patients should live in ordinary neighborhoods, especially unimpressed if the designated neightborhoods were theirs. The Department of Mental Hygiene apparently never did develop a contingency plan that would permit them to deal with community resistance. Further, the Department of Mental Hygiene doesn't quite understand that, when mental patients or state school patients are released, it would be best to diversify their placements, not consolidate them in one or a few locations. And when the residents of Long Beach, New York complained to the State Department of Mental Hygiene that, in fact, the Department was creating new quasi-institutions in the community with the purchase of converted motels or hotels for subsequent assignments of large numbers of mental patients to these facilities, the State Department of Mental Hygiene responded with lectures to the citizens on their moral responsibilities and the need for increased community acceptance and good will.

The irony of it all is that the community lay people had a much more insightful analysis of the situation, the problems, and possible solutions, than the State Department professionals. The community group said, "O.K., send your mental patients into our neighborhoods. However, if you want them to live in a normalized fashion, in ordinary neighborhoods, don't congregate them together. Permit us to continue to have normal communities—not places where there are large numbers of peculiar or different people, herded together in abandoned, dilipidated, or second-rate hotels."

The State Department of Mental Hygiene did not heed the community's advice, then pleas, then threats. They merely lectured at the community, to be good citizens, to accept differences, to have forebearance, to understand, to possess all of those virtues that the professionals in the State Department seemed to lack themselves. So we had to backlash, and a new and strange coalition of conservative average citizens—people such as our own mothers and fathers, our friends—and the *New York Times*. Wonders—and those who answer the question negatively are probably correct—will they ever cease? And so, we have a new state policy to slow mental patients' releases. Don't suggest discharge to them lest they request release. Cool it, boys; the natives back in the boonies are getting restless. Even the New York City sophisticates have "had it."

> "The State Department of Mental Hygiene, defying city officials, plans to transfer 240 mostly helpless mentally retarded patients from Willowbrook to a four-story nursing home on Staten Island that has never been used because the city twice refused it a permit to operate . . .
>
> "The (community) residents stress that they were not opposed to the plan because it would bring retarded people into the community, but because the nursing home in question would be a 'prison' and a 'zoo.'"[6]
>
> "The city's top health officials and the heads of psychiatry at leading hospitals here have

> clashed with the State Department of Mental Hygiene over state plans to reduce drastically the number of beds planned for the new Bellevue psychiatric center . . .
>
> " 'Everybody who is a top professional in the city is absolutely agreed that the number of beds must not be cut' said one of those at the meeting . . ."[7]

Rebuff after rebuff; yet the dauntless State Department continues to seek solutions to the problems of this crazy business. Like Don Quixote jousting with windmills, our mental health leaders, ever sensitive to both the community and current professional metaphors and slogans, would evacuate institutions by creating new ones in the community, would evacuate them altogether. So they claim, but they don't have an analysis of what must follow. They are dedicated to "integration" and "humanization," as they integrate inmates by segregating them in nursing homes, and humanize the large institution by dehumanizing the community. Unfair? Probably! Is there another way of analyzing this news? Certainly! Yet, does the Department deserve the censure? No, if nobody deserves censure for what we have perpetrated; yes, if anybody deserves censure.

> "The Elmira School Board was told Wednesday afternoon that the district may receive nearly $1 million more in state operating aid next year than was received this year . . .
>
> "Weeks (the district business manager) said that he had nothing in writing and cautioned that $700,000 of the aid increase might have to be used in programs for the handicapped and students with special needs.
>
> "However, School Superintendent Dr. Paul R. Zaccarine said that his impression is the district already offers the programs for which the $700,000 would be earmarked"[8]

Find a way, boys. Bring in the resources but, unless there is no other choice, don't use your precious scarce funds for the handicapped. You have more important priorities, even if those funds were earmarked for the handicapped.

> "Manly Fleischmann, the Buffalo lawyer who was chairman of the Commisson (on the Quality Cost and Financing of Elementary and Secondary Education in New York State), was asked last week what had happened to his recommendations (made two years earlier). His first reaction was to laugh . . .
>
> "Cost of the Commission: $2 million."[9]

So, again, what else is new? Problems occur, statements are made, tempers rise, newspapers report, commissions are appointed, funds are allocated, and the more things change the more they remain the same; except, things remain the same differently from the ways they remained the same before. And, so it seems, that's all the people want. Things can remain the same so long as the color and rhythm of the sameness change hues and tempos from time to time. The major task is not to change but to satisfy everyone: first, the conservatives, but, also, the radicals; the conservatives, because they are in control and pay the bills and the radicals, because—if they are not under control—they will try to upset the delicate balance between no-change that appears as change and no-change that's discovered for what it is. Satisfy everyone, those who pay the bills because they pay the bills, and those who are potentially, or really, irritating to the true power groups.

The ultimate aim is to not only "freeze" the present but establish some type of "warrant," a hold on the future. It appears that one of the goals of a large segment of our society is to guarantee to their progeny what was guaranteed, and later delivered, to them—places of relative prominence and affluence in their society. And who could question that ideal? Who doesn't want to prepare for his coming generations? Who doesn't want a world for his loved ones that is at least as safe, and cozy, and comfortable as it was for him? The answer is obvious: those who never had anything, those who want something different for their children, if not for themselves. So, there is a conflict between variance and invariance, between the haves and the have-nots, between those who are more and those who are less selfish, between those who have more to protect and those who have more to gain, between the power block and the powerless, between the *New York Times* for the underdog and the *New York Times* for the overlord.

All ideas have histories, and the proper study of the histories may illuminate for us not only what occurs in the "name" of certain ideas but what the ideas actually mean. That's the first lesson; a goal or an idea is nothing without its history, and then it's only something in a special context and perspective. Therefore, let's continue examination of a few of the more provocative ideas that we seem to be romancing at this time. And, if these love affairs weren't made in heaven, there may be a more appropriate place to bear witness to such unions—and if not to the marriages themselves, to what they have become.

Mainstreaming, The Community, and The Teachers' Union

As enunciated again and again, during informal discussions and in official or scholarly documents, our nation's educational leaders have now decided that handicapped children are best served in integrated settings. "Mainstreaming" will be, if it isn't now, the law, if not the practice, in this land. The Regents of the University of the State of New York urge a greater commitment by society to the education of handicapped children, with the primary responsibility for programs placed with local school districts and as integral facets of public education (1973). The litigation in our field exemplifies the centrality of the "integration-mainstreaming" issue.[10, 11]

An analysis of the official reports of the various public committees and commissions responsible for formulating national policy on behalf of the handicapped indicates the marked escalation of concern about the integration issue. From the first annual report of the National Advisory Committee on Handicapped Children to then United State Commissioner of Education Harold Howe II in 1968[12] to its subsequent reports to later Commissioners James E. Allen, Jr.[13] and Sidney P. Marland, Jr.,[14] mainstreaming does not appear to be an important issue, at least an issue that deserves identification in annual reports. Contrast its virtual total absence during the late sixties and early seventies with the most recent report of the Committee.[15] Now, priority recommendations reaffirm the Constitutional right of all handicapped children to a tax-supported appropriate education, regardless of their physical or mental capabilities. Further, the Committee now urges that regular education environments should be made available and, when there are differences between, for example, parents and school authorities, due process procedures should be operational to insure an equal educational opportunity for each child.

A comparable analysis of *MR '67*,[16] the first major policy statement of the President's Committee on Mental Retardation, and all of the subsequent reports, including its most recent one in 1974, *Silent Minority*,[17] illustrates a major shift in policy discussions from an earlier deficit-oriented and categorical segregation model, based on the assumption that handicapped people need special and separate services to be delivered by professionals, to an avowal of principles of: advocacy, normalization, least restrictive alternatives, due process, and rights rather than privileges. Witness that, in 1967, the President's Committee appeared to be very proud of the fact that there were nearly 700,000 children in special classes for the educable and trainable mentally retarded. Note that, in 1967, there was little distinction made between special class and special education; special education was special class. Note, again, how "needs" were discussed in 1967, in terms of more services, not "open" or integrated services. And, although in 1974, the realities for people with special needs may not be very much different, the rhetoric surely is—with the language today expressing concern for an individual's rights, his freedom, his entitlements, his need to be a part of a world that includes rather than excludes him.

I don't know of a professional organization, or a municipal, state, or federal system or agency, that is plainly antagonistic to the mainstreaming principle. Certainly, there are individuals within those organizations and programs who take a dim view of the mainstreaming movement. However, mainstreamers seem to have the segregators on the run, at least for now. Or do they really?

Item 1: A debate is currently smoldering in Syracuse, and it will probably rage again as it did a year or two ago. It's a complicated matter, as all of these things are; suffice to say, I think there is one group who want a special school for the trainable retarded and another group who believe that a special school is neither desirable educationally nor responsible fiscally.

Although they have difficulty in believing they've won, the special schoolers have won; the Syracuse City Council, the Board of Education, and the school administration have all agreed that a special segregated school for trainable children is necessary, desirable, and defensible. Those of us who have raised questions concerning the need for a separate school, during a period of significant pupil enrollment decreases (e.g., a 600 drop for 1974-75 alone) and in a supposedly new egalitarian era, have been accused of insults against children. It seems ironic, at least to me, that in an age when unusual efforts are being exerted by local communities to integrate, for example, Black children, more unusual efforts are being exerted to segregate retarded children. While the courts in Boston and Detroit insist that minority youngsters be integratated—irrespective of long bus rides and significant program modifications and costly expenditures—the Syracuse City Fathers continue their plans to segregate handicapped children, whatever the costs.

Item 2: Syracuse is in Onondaga County and, reflecting the same "disease" of that city, the County Board of Cooperative Education (BOCES) has been seeking citizen approval for an additional new segregated school for the handicapped and for those youngsters enrolled in what was once called vocational education but now is referred to as career education. Probably, more out of anger in again having their "pockets picked" than for any reasons concerning principles or morality, the voters recently turned BOCES down—for the first time in New York State history, denying a BOCES program the opportunity to expand its segregated mission.

Why does BOCES want a new school? Again, the polemics run rampant during these kinds of discussions and, trying to be fair but probably not succeeding very well, I should point out to anyone who hasn't noticed that I am singularly unimpressed with any efforts to expand or strengthen segregated settings for people. Having said that, I can now claim that the special education officials in the county want a new school because, since the beginning of organized society, bureaucrats want larger budgets, more staff, bigger and newer facilities, and control. Certainly, the current segregated school for the trainable mentally retarded in Onandaga County is inadequate. It is old, crowded, inaccessible to many families, and inappropriate. On the other hand, the only virtues I can see in constructing a new school is its newness and, possibly, its greater square footage per child. Yet, irrespective of its newness, size, or even beauty, a segregated school is still a segregated school; it will be centrally located and, therefore, inaccessible to many families; it will not permit the integration of the handicapped with the nonhandicapped and, as importantly, vice versa. However, exactly as with the Syracuse group, time is on the side of the county segregationists. Someday they will have their new school, if not after the new referendum, then the referendum after that, or the next one, or the next one.

Item 3: Ideological banners fly from the public relations staffs of the New York State Department of Mental Hygiene, proclaiming: deinstitutionalization, community programming, advocacy, priority reassessments, normalization. Yet, in the city of Syracuse alone, during the past three years, more than $50 million (plus millions more in interest) has been expended by the State Department of Mental Hygiene for the creation of new segregated insitutions.

The Syracuse State School, created in 1854, the oldest state school for the mentally retareded in North America in continuous operation on its original site, has now been torn down and rebuilt, almost brick by brick, on that site. Where, formerly, it had a resident population of 250, the new state school is built to serve 750 residents. Permit me to remind you that not only is the facility larger but it is no longer a state school; we now have in our community a brand new concept as well as facility, the Syracuse Developmental Center, that has replaced the old state school. Similarly, what was once the small, essentially outpatient, Syracuse Psychiatric Hospital is now the brand new $25 million Hutchings Psychiatric Center, capable of "bedding down" 750 inmates.

Item 4: "Everybody" in Syracuse had agreed that we should return state school residents to the community as quickly as possible. Therefore, the school's director acquired a small residential facility to develop as a group home. Neighbors-to-be learned of this plan and, very quickly, drew up a petition which they presented to Mayor Lee Alexander; said petition denying any hostility to the concept of community integration but, on the other hand, providing a number of compelling reasons why this community residence would be inappropriately placed in that particular neighborhood. Mayor Alexander agreed with the petitioners. End of group home plan. And, when I was interviewed on television soon after the Mayor's decision, I received a number of rather hostile calls and letters, the following among them:

> Dear Dr. Blatt:
>
> You should live next door to mentally retarded like I do. On the weekend they go all over surrounding streets, scavenging big pieces of metal trash and wooden trash (they have superior physical strength to make up for lack of mentality) and so on Sunday the peace of the Sabbath is broken by their hammering on it (trash is picked up Monday a.m. in our neighborhood).
>
> One looks about 30 and plays like a little kid. The other looks about 7 or 8. He thinks he is a method of transportation all the time. And goes down the street making like a

motorcycle, an airplane, a racing car, etc. Sometimes he just stands and yells as loud as he can yell. They both do this.

They have not one but two dogs that bark 24 hours a day.

I say these people have no business living in a normal community—whoever sold them the house should get a medal!

I say these people should be provided with a community of their own; live with their own kind.

I understand there is one at Liberty, New York. I sure would like to be able to send these people there.

(Signed)
Has had it.

Item 5: Now, the most puzzling for last, the quintessential hypocrisy for the finale. My friends in the Syracuse City Schools, many of whom have been students in my classes, others of whom have served with me on committees, a few of whom are—truly—my friends, collectively agree that handicapped children deserve to be integrated in regular programs. Yet, circumstances and promises made by their predecessors force them to support the construction of the aforementioned new segregated school for the trainable in Syracuse. Yes, precedence, teacher prejudices, and practicality require them to continue their elaborate segregated special education program. However, if they had their way in the best of all possible worlds, they would integrate more children with special needs, especially the mildly handicapped. Similarly, members of the Board of Education agree fully with the concepts of mainstreaming and normalization.

And, as if to add insult to injury, in spite of public pronouncements in support of the principle of integration, the Syracuse Board of Education, with the concurrence of school officials, has entered into a negotiated agreement with my friends in the Teachers' Union which discourages school authorities from requiring regular class teachers to accept handicapped or disruptive youngsters in their programs.

It is the ultimate nonsequitur to claim to foster integration in a system where those same claimants support segregation. Not only is this crazy business, but it is also funny business.

The Year of the Child and Other Indecencies

Surely, there are reasons, related chains, that make indecencies almost inevitable. The reader has a right to ask why these indecencies occurred. I have some notions to "explain" them and you probably will develop yours. But I don't have truths, and you might not find those either. Someday, maybe, but for now, I only claim to collect and publicize indecencies, not adequately to understand them.

Item 1: Sometime during the spring of 1970, an administrator in the Massachusetts Department of Mental Health was in San Francisco. Upon his return, he remarked to colleagues that the California Chinese seem to always have a Year of something or another, and he suggested that this would be a good time for Massachusetts to have the "Year of the Child."[18] The idea caught fire. The Commissioner of Mental Health announced that 1971–72 would be the "Year of the Child" in the Commonwealth. Finally, attention would be given to the needs of children, priorities would be reordered, and an increased proportion of the Department's resources and programs would be allocated for children.

Unfortunately, this commitment to children was made after the Department of Mental Health had submitted its budget requests to the legislature. No resource shifts would be possible. Additional state assistance was equally impossible. Additional federal funds to meet the commitment didn't materialize. The "Year of the Child" was never more than a gigantic hoax, a public relations ploy created out of innocence, "implemented" by the cynical, and finally exposed publicly amid embarassment and frustrated disclaimers from the insiders and righteous anger from the muckrakers. The grand objective, the beautiful logo on thousands of wall posters, the fervent promises made, were all garbage, like confetti after the parade, like a kewpie doll the morning after in the noon day sun. All this from the chance notice of a wall poster in a Chinese restaurant. How easy it is to do something, and how difficult to accomplish anything.

Item 2: I can hardly wait to complete this next section on advocacy. In my study, I am surrounded with piles of books, monographs, chapters and papers—all dealing with the definition, theory, implementation and practice of various forms of human help we now term "advocacy." Who really knows, but that, when I finish this section, I will find a paper I wanted to use earlier but is now hopelessly irretrievable in a morass of advocacy paper. But, to paraphrase what a colleague once said in an entirely other context, do we have a knowledge explosion on advocacy or merely a paper explosion? One wonders, and here's why.

Wolfensberger described the various advocacy roles for children, including those that are primarily instrumental, some instrumental and expressive, and even one that is primarily expressive, the advocate-friend.[19] As he and others noted, there are advocates who assume roles as guardians, friends, adoptive or foster parents, legal advisors, and "helpers." However, the one characteristic advocates must have in common is a partisanship, a primary interest to serve the client. Literally, the advocate is one who pleads the cause of another person, not conflicted by self-interests or loyalty to an organization or to one's profession. This partisanship, as a matter of fact, is one of the significant factors in the case Wolfensberger makes for the utilization of citizen-nonprofessional advocates on behalf of people who are mentally retarded.

The idea of advocacy has so captured the thinking in our field that, as happens to all good ideas, there are now groups attempting to appropriate—capture for themselves—the idea. Why must the advocate be professionally disinterested and nonpartisan, preferably a lay person? Why indeed? Wouldn't it be best for an advocate to be a spokesman for the deliverers of services so the program as well as the advocate can he held accountable for the work of the system? Would it? Some people think so.

As a matter of fact, the Regents of the University of the State of New York not only believe this but have developed a sure-fire method to implement an advocacy system that, in my opinion, will only lead to the destruction of the concept of advocacy in the public schools of New York State. The Regents have designed an ingenious method to co-opt an idea intended to serve clients but which now would serve the providers.[20] They recommend the creation of a new advocacy system for children with handicapping conditions. They claim that a good advocacy system requires strengthened cooperation among agencies in the public and nonpublic sectors. Therefore, to be effective, any system of advocacy and service delivery must provide for cooperative arrangements agreeable to the Commissioner of Education and to those people responsible for the supervision of institutional programs at the state level. Consequently, the Commissioner of Education should be given the responsibility for the overall supervision of programs for handicapped children. Further, the state-wide system of advocacy should be vested by statute with the Commissioner of Education, and ". . . local school districts, BOCES, and other state agencies (should) have a proper role to play and that, wherever possible, parents represent the starting point."

Imagine a state-wide advocacy system, where the advocate is employed by the state yet uses his expertise or services only to serve his clients, with the chief advocate being the Commissioner of Education, and with other state and local agencies and individuals having proper roles in that system—including lastly, but including wherever possible, parents. Just imagine!

Item 3: During the past several months, the R. J. Reynolds Tobacco Company, manufacturers of Camels, have been conducting a vigorous advertising campaign to attract the "honest and independent" smoker. Each of the advertisements in this series began with the question, "Can you spot the Camel Filters smoker?" The scene is in an airplane, at a party, or on the beach. Various people are pictured, saying something or doing something or appearing in some distinctive manner. The reader is to deduce who smokes Camels and, presumably, why. Surely, you have seen these ads. I have but, as with most advertisements, my observations were mindless; for so much of today's reading, advertisments or otherwise, mindlessness is a fairly safe and respectable condition to be in. If not for Liz Smith, an attorney who is a member of our Center on Human Policy staff, I never would have noticed that a particular Camel ad was vicious, bigoted, and unfair—but as typical of our culture as apple pie and baseball games. Among five other people on the beach, ranging in "beautifulness" from zero to everything, is Tyrone Shulace, "beach pest." We are told in the ad that the "58" on his shirt stands for his I.Q. Further, Tyrone thinks that "off shore drilling is something Marines do." He smokes "Huff'n Puff" super filtered cigarettes. Obviously, that makes him retarded, unappealing, and deserving of whatever ridicule is heaped upon him.

Liz Smith wrote to the president of the R. J. Reynolds Tobacco Company, Mr. Collin Stoker of Winston-Salem, North Carolina. Within a week, she received a reply from C. A. Tucker, Vice

President and Director of marketing for the company. He was apologetic. He said that:

> "We do our best to create advertising that will appeal to large numbers of people. We have found one of the best methods to be humor. The 'Can you Spot' ads are intended to be much like a cartoonist's caricatures with the larger-than-life portrayal of the subjects not meant for literal interpretation . . .
>
> "We have a great deal of empathy for the kind of public spirited work you are doing (our company supports local organizations involved with mental health)."[21]

And, I think Mr. C. A. Tucker is right. This ad will appeal to large numbers of people. It will be thought very humorous. And, besides, R. J. Reynolds does have a lot of empathy for the kind of public spirited work we are doing. And, I am sure, the company supports local organizations involved with mental health. They're as clean as a hound's tooth.

Item 4: Behavior modification, operant conditioning, behavior shaping, there are those and many names for a relatively new technique that has fast replaced psychotherapy as America's mental aspirin. The following bizarre story[22] is not intended to repudiate the importance or effectiveness of behavior modification techniques. There is no intention, at least on my part, to dissuade the reader concerning the great promise this method holds if used judiciously and appropriately. Rather, the Miami Sunland Training Center scandal is another indication of good ideas gone awry, good intentions misanthropically realized, potentially good people turned sour.

Sunland Training Center, in Dade County is a state institution in Florida, domiciling 900 people, each labeled mentally retarded. Like most state institutions, some of the residents are very retarded, some mildly retarded, some "retarded" only because they had once been labeled retarded. Like most large institutions, the age range represents a very wide spectrum indeed, young children to adults; and the range of behaviors represented at this institution is uncommonly broad and multidimensional. In essence, Sunland has a very heterogeneous group of residents, some of whom are at least adequately identified by the label "mentally retarded." Enter into this scene a new superintendent, one with a good reputation for "getting things done," for doing the right things, for being truly concerned about the mentally retarded. Enter also a psychologist who is given a free hand, who believes he has answers to the developmental problems these residents present, who is strongly devoted to behavior modification techniques as the foundation, the beginning direction, for behavioral improvements.

The consequences: homosexuals compelled to wear women's underwear; "thieves" who steal Cracker Jacks required to eat bars of soap and wear special signs noting each as a "thief"; those found masturbating, forced to masturbate in public; one inmate, who defecated in his pants while in seclusion, required to hold his soiled underwear under his nose before washing the pants out in the toilet; another "thief," caught stealing Sugar Pops, placed in restraints except to go to the "potty"; another boy who didn't want to go to bed locked up in a seclusion room; and on, and on, and on—children cleaning up their own vomit, rinsing their mouths with soap, denied meals, denied "privileges," tortured. Surely, this is not what Skinner planned for a new Walden. Surely, this is not what Barrett, Lindsley or Sidman envisioned. But, in this business, good ideas are often spoiled and altruistic motivations are corrupted.

Item 5: A letter to the writer of this chapter.

> "In reviewing your book, *Souls in Extremis*, I am informed that the pictures in "Central" State School are in reality . . . State School. I would suggest that the material is quite out of date . . . the conditions you mention have definitely changed.
>
> "One of my main criticisms would be the picture of the Community Store. I cannot identify the page as it does not have a page number, but the entire paragraph there is incorrect. The interest for residents is strictly regulated by law. There is a small amount left over because of bookkeeping difficulties. This amount is never used for the Community Store, never used for a retirement banquet, employees' gift fund, etc. The purposes for which this money is used must be itemized and presented to the Department of Mental Hygiene for approval. I take strong objection to this . . ."[23]

But here is an entirely different letter, from the above superintendent's immediate supervisor:

> "By chance, I must confess, I was going through the Department library and found your book, *Souls in Extremis*. I have not been

able to start reading it yet but was caught by the pictures in the chapter, 'A Photographic Essay, 1971,' by Mark Blazey. What struck me was your straightforward description of Community Stores and the use of money for the benefit of employees. This came to my attention last Christmas when I found that these funds were used to pay for employee Christmas parties. I am enclosing a memorandum which was sent out concerning this problem and I think procedures are such that this misuse of money should be a thing of the past."

STATE OF
DEPARTMENT OF MENTAL HYGIENE

February 15, 1974

DIVISION OF MENTAL RETARDATION
AND CHILDREN'S SERVICES

Memorandum No. 74–5

TO: State School Director, Deputy Directors for Administration
Central Office Distribution Schedule 2

SUBJECT: Review of Community Stores, Donations and Patient Accounts by an Institution Ad-Hoc Committee

No proposed budget for community stores, donations, or patient interest accounts for fiscal 1974–75 will be accepted unless reviewed by a Committee whose size shall not be more than seven (7) members and whose membership shall consist of one-third parents, one-third resident, one-third employes, and one member of the Board of Visitors.

The Division policy will be that all funds from these sources shall be used primarily for residents' benefit. Recommendations will be made to the Director who will make final decisions.

Each institution will notify Dr. . . . 's office in writing upon the selection their review committee.

This memorandum will be in effect until superseded by future directives.

The supervisor adds:

> "I am also enclosing our memorandum on burials and maintenance of cemeteries (also discussed in book, with our treatment similarly citicized by aforementioned superintendent) which hopefully will start solving this problem."

August 12, 1974

DIVISION OF MENTAL RETARDATION
AND CHILDREN'S SERVICES

Memorandum No. 74–30

TO: Directors, Deputy Directors, Clinical and Deputy Directors for Administration of all Division of Mental Retardation and Children's Services Facilities
Regional Directors
Central Office Distribution #2

SUBJECT: Burials and Maintenance of Cemeteries

It has come to the Division of Mental Retardation and Children's Services' attention that many graves in our institutional cemeteries are unmarked or marked only by a number. To correct this situation, the Division of Mental Retardation and Children's Services enunciates the following policy:

1. All graves in Mental Retardation and Children's Services' facility cemeteries will be distinguished by a marker with the person's name, date of birth and death, and appropriate religious symbol. No numbers will be used.

2. All burials will have a religious ceremony, unless such a ceremony is waived in writing by parents or guardians.

3. All state cemeteries will be maintained, and whenever possible, no new plots will be opened and community cemeteries should be used.

4. All graves, whether in state or community cemeteries, will be distinguished by a named marker.

The correspondent continues:

> "The other things that are photographically highlighted are obviously more difficult given the inertia of the system. However, we have a number of projects which I hope will make some dent in the problems."[24]

The institutional superintendent claims that I am unfair, that the problems we portrayed have either been corrected previously or were never present. Her supervisor informs me that he has observed the same institutional abuses we described. He also tells me that, given the inertia of the system, other aspects of this photographic essay will not be corrected very easily. Yet, I am threatened in a subsequent letter by the superintendent who warns me that, because she is an advocate for the residents, she intends to "pursue this (our) transgression further." We have been waiting and, although I have heard several rumors that I will be sued, our last communication from this superintendent was January 23, 1974. Who is deceitful? Who are the advocates? And, if as claimed, the superintendent is an advocate, what does advocacy mean?

Innovation is the Name of the Game

Innovation is the name of the game, but it's not the stuff in the game. We may convince ourselves that we are truly in an innovative era in mental retardation. There is a plethora of monographs, books, and full journals devoted to innovative appraoches to evaluating, placing, treating, dealing with, serving, and counting the mentally retarded; there are even claims that innovative approaches to paying for it all are now available. We read about innovation in special education[25] and innovation in other mental retardation settings[26] and we are tempted to believe. However, notwithstanding instructional materials centers, engineered classrooms, "hot" new dyslexia treatments, the effects of early educational intervention programs, new directions, and exciting frontiers emerging, notwithstanding the wish to believe, the jaundices and disappointments of the past remain, and therefore one tends to doubt. It isn't that we don't want to believe; we do or, I should say more correctly, I do. It's not that the evidence isn't piling up; we now have a Mental Retardation Source Book[27] and, believe it or not, I am currently serving on a committee that is optimistic enough to think it can develop a Mental Retardation Fact Book. Who would have thought that?

Nevertheless, I don't think that there is very much innovation in our field: first, because innovation requires new ideas (that's always a rare commodity) and, secondly, because we seem to be deliberately planning to achieve the anthithesis of innovation and diversity.

Essentially, ours is a monolithic system, a single block of ideological stone; ours is a massive and solid, uniform, no-option, no-alternative, slot machine type of strategy that would seek the single best method, the single best procedure, the single best something or anything.[28] The Monolith is not the special class, or even the segregated institution, or any other special setting or procedure or model. Rather, the Monolith is the one way, the unavailability of alternatives for clients, families, therapists and others concerned with the education and treatment of people with special needs. The Monolith supports "innovative" programs that evolve into either carbon copies of what is currently available or distortions of something that was once good, bad, or indifferent but will, surely, become tomorrow's new fad or the "magic" of the next modern-day alchemist. One thing that I've learned from all of this is the value we must assign to truly creative thinking and planning; it's an infrequent occurrence, often unrecognized, usually feared, and commonly disdained.

Essentially, I am claiming that innovation is more a myth, or a dream, in our field than a regular occurrence. Our schools and teachers' colleges are akin to national franchised educational supermarkets that encourage almost-infinite varieties of methods and curricula, that foster open schools and contiguous traditional schools, that support both free schools and special schools, and—in spite of the seeming flexibility—demand an oppressive conformity to the products, the methods, the materials, and the curricula available in the supermarkets. Sameness of mind is the mortar that binds and strengthens the Monolith—in the elementary classrooms, in the teachers' colleges, and even in the minds of the consumers. So, too, our mental health planners now struggle to develop not only better but the the best health delivery systems, each in their ways promoting an invariance of opporunity and a technological influence on people that usually leads to the technology as the end, not the means.

The consequences are around, everywhere. We advertise segregated schools, open schools, free schools, and ungraded schools in the educational supermarket, for the same reasons others advertise Chevrolet, Camels, and Popsicles. We advertise group homes, halfway homes, regional centers, and even large institutions because we believe we have the best product or, in any event, we want to convince the consumer that, all things being equal, our products offer the most value. As a result, our field presents an appearance of innovation, when it is more a striving towards conformity and agreement. We offer many methods and tactics, not because we prefer diversity but, rather, because we are uncertain as to what is best among competing claims. We encourage new models, not because we believe that thoughtfulness emerges from struggling with the creation of a new model which is only for the good, but rather because we hope that the new model will offer a better solution and, eventually, a universal solution. We develop new curricula, new delivery systems, new techniques and prescriptions, hardly ever because we believe it would be instructive to our colleagues to inform them about how we attempted to solve various human problems, but because we are unable to believe our colleagues think or know enough to solve their own problems. That is, we seem to believe that the value in developing treatment models lies in how they can help us understand better the process in developing prescriptions. Fundamentally, the majority among us believe that there are best methods and best prescriptions, and we must train technologists to teach, to dose, to supervise, to serve others with those "best" procedures. There is a minority which believes that, although technicians will always be needed and are important, professionals must be prepared not as technicians but as creators of environments; there are no best methods in the human services; the process of creating a human environment may contribute more to to the excellence of that environment than the objective and technical characteristics of the environment itself.

Definitions, Labels, Incidence and Prevalence

Wedged by Executive and Squeezed by Academic Views

Years ago, when I first began seriously to study institutional life, I learned that, in New York State, residents of state schools were labeled "material" and their attendants and supervisors were labeled "items." More recently, while attending a meeting on the so-called geriatric problem in mental retardation, I learned that human beings are called "inventory" by some state department employees who have been designated responsible for their care and humane treatment. During the years, I have learned that labels are important, because they picture the feelings we have for people and things, and because they serve to peel away the concealment of our prejudices.

Labels may not be of consequence in a clinical setting; in fact, their usage with individuals should be restricted, if not discouraged. However, there are people who need service and the administrative assignment of resources to programs and groups requires the utilization of identifiers, labels. We can't ven discuss policy priorities, much less programs, without naming people and things. For better or for worse, we have and will continue to have, and suffer with, labels. Hence, we will need to contend with an "epidemiology" of mental retardation—notwithstanding the knowledge that mental retardation is neither a disease nor a condition with "lawful" characteristics.

The labels we use are critical in understanding that epidemiology, because incidence and prevalence estimates have little meaning when separated from a definitional context. Therefore, notwithstanding the President's Committee on Mental Retardation, which has reported that there are 6 million mentally retarded individuals in the United States (a convenient application of the three percent estimate) and other approximations, I believe it remains essential for us to review what else may be known about these complex matters. I begin here with where I began the paper itself, discussing metaphors, language, and the relationship between our words and our values. We should begin by noting again that incidence and prevalence data are not grounded only in objectively derived disease entities.

The American Association on Mental Deficiency has recently revised its definition of mental retardation. Before 1959, there was more or less general agreement that the incidence of mental retardation is approximately three percent. That is, mental retardation was assumed to be normally distributed in the population and it was further agreed that the psychometric "cutoff" would be seventy-five I.Q. or one and one-half standard deviations away from the mean. In 1959, the Association's terminology and Classification Committee, chaired by Rick Heber, redefined mental retardation and, included in the revised definition, there was the statement that subaverage intellectual performance refers to a psychometric score which is greater than one standard deviation below the population mean on tests of general intelligence.[29] With that change in definition, 16 percent of a typical population would be, psychometrically at least, eligible to be designated as "mentally retarded."

In 1973, a subsequent committee of the Association, now chaired by Herbert Grossman, again revised the definition to include as mentally retarded only those who are "significantly" subaverage in intellectual functioning, where "significantly" means performance which is two or more standard deviations from the mean or average of the tests.[30] With the figurative, and possibly literal, stroke of Herbert Grossman's pen, a committee sitting around a conference table reduced enormously the potential incidence of mental retardation, never having to see or dose or deal with a client, only having to say that, hereinafter, mental retardation is such and and such rather than this or that. We cannot redefine measles, or cancer, or pregnancy with such external procedures. It's obvious; mental retardation and emotional disturbance, and even such seemingly objective conditions as blindness and deafness, are less objective disease entities than they are administrative terms; they are metaphors more than anything else.

It is important to understand that merely having a low I.Q. neither legally nor functionally jeopardizes how society views a person or deals with him. Sixteen percent of the population have I.Q.'s below 85; three percent of the population have I.Q.'s below 75; but probably no more than one percent of the population are ever in their lifetimes administravely adjudicated as "mentally retarded." This is by way of saying that the incidence, prevalence, and characteristics of mental retardation depend upon such influences as definition and criteria, program supports, cultural value, social class, and other factors that have more to do with political and administrative rather than biological or psychological matters. This situation exists across all so-called disability areas, and consequently, estimates of various categorical handicaps vary from study to study, from culture to culture, and from time to time. Disability means no more or less than being placed in a special class, a special program, or a special category or setting, as a consequence of that disability. The most relevant definition of a disability must refer to the fact that it is essentially administratively determined.

Incidence and prevalence estimates, predicitions of program needs, and cost-benefit analyses are extraordinarily hazardous when dealing with these diverse administratively-defined populations. For example, in one state, attempts are made to integrate so-called educable mentally retarded children in regular grades, in another area (e.g., Prince Edward Island, Canada) such youngsters are in regular grades and are not even thought of as "mentally retarded." In yet another state, every effort is made to place as many children as possible with I.Q.'s less that 75 in special classes for the mentally retarded. Then, we might ask, what is the prevalence of mental retardation in the public schools when, on the one hand, there are school systems that deliberately attempt to identify such children as retarded and others, equally interested in their well being, that deliberately attempt to integrate such children fully into the mainstream of educational life?

Table I summarizes prevalence estimates of handicapping conditions obtained from several recent studies. Some cautions should be emphasized: with the exception of our yet unpublished preschool data, summarized in Column One, the prevalence estimates are for age groups 5 through 19. Therefore, I am presenting prevalence of handicap among preschool children with prevalence estimates for school age children, while entirely neglecting adult prevalence rates. Secondly, none of these estimates account for what is now called minimal brain dysfunction, learning disabilities, or Strauss Syndrome. Intentionally, I have not included prevalence estimates for this condition if, indeed, it is a separate condition; those that have made attempts to estimate the prevalence of learning disabilities indicate data ranging from a 5 or 6 percent estimate to 20, 30, and 40 percent. Next if should also be noted that some of these prevalence estimates did not include multiple handicaps as a separate category; rather, they chose to indicate only the primary handicapping condition. Further, Table I hardly illustrates the enormous range of estimates available. For example, a recent Rand study on services for handicapped youth summarizes prevalence rates reported by 11 different groups.[31] They range: in total prevalence of handicapping conditions, from 4.08 percent to 24.50 percent; in mental retardation, from 1.54 percent to 7.00 percent; in speech impairment, from 1.30 percent to 5.00 percent; in emotional disturbance, from .05 percent to 5.00 percent; and in learning disability, from .03 percent to 7.00

TABLE I.—*Prevalence estimates of various types of handicapped children*

Handicap	Prevalence estimates by percent				
	1 [1]	2 [2]	3 [3]	4 [4]	5 [5]
Educable mentally retarded	0.5	2.0	2.3	1.30	1.30
Trainable mentally retarded				.24	.24
Hearing-impaired	1.1	1.5	.575	.10	.575
Visually handicapped	.6	.2	.1	.05	.1
Speech impaired	3.4	2.0	3.5	3.60	3.5
Physically handicapped	1.0	1.5	.5	.21	.5
Brain injury and learning disabilities	1.7	(6)	1.0	1.12	1.0
Emotionally handicapped	1.0	2.0	2.0	2.00	2.0
Multiple handicaps	(6)	(6)	(6)	.07	.07
Total	9.3	9.2	9.975	8.69	9.285

[1] Estimates based on a Syracuse University-Systems Research Inc. Head Start questionnaire; T.M.R. and E.M.R. combined; no estimate on "Multiple Handicaps."

[2] Estimates by Romaine P. Mackie and Lloyd M. Dunn, College University programs for the preparation of teachers of exceptional children, USOE bull. No. 13, Washington: GPO, 1954.

[3] Estimates prepared for Bureau of Education for the Handicapped, USOE, in "Estimates of Current Manpower Needs in Education for the Handicapped, 1968–69," Washington, December 1968.

[4] Estimates used by Rossmiller, Richard A.; Hale, James A.; and Lloyd E. Frohreich, "Educational Programs for Exceptional Children: Resource Configurations and Costs." Madison, Wis.: Department of Educational Administration, University of Wisconsin, 1970, p. 129.

[5] Conservative estimates used by "The Fleischmann Report on the Quality, Cost, and Financing of Elementary and Secondary Education in New York State," Viking Compass, vol. II, p. 260.

[6] No estimate.

percent. Lastly, one should mention that, for most people, in our field, prevalence and incidence estimates are either meaningless or valueless, or both. Many such colleagues would claim that institutions, or schools, or clinics have what they have. What possible differences could these data offer?

While you may legitimately inquire, therefore, what value can prevalence studies provide, you might also ask what other comparable data are available to permit us to plan better, however crudely. And, while you ponder that unsatisfactory question, we should return to Table I, and our data, and—eventually—some recommendations. The reader will find a rather striking similarity between data derived from our Head Start questionnaire and other estimates—with the exception of the prevalence of mental retardation. Ours is low (0.5 percent) in contrast with estimates of 2 percent and 2½ percent in the others studies. We believe this discrepancy is accounted for in our earlier discussion on factors influencing prevalence rates. Further, our reported low prevalence of mental retardation is entirely consistent with the numerous so-called educability studies concerned with the preschool deprived.[32, 33] Specifically, we account for the low prevalence of preschool mentally retarded children in communities that traditionally include high prevalences of school age mentally retarded children to be a function of the nature of this thing we term "mental retardation". Mental retardation is essentially unidentified in the preschool years except when it is accompanied with central nervous system pathology or clinical stigmata and, therefore, usually with moderate or severe disability. So-called cultural familial mental retardation, quite common in later years, is essentially nonexistent among infants and preschoolers. What was probably reported to us as "mental retardation" by Head Start Centers were observable stigmata and moderate or severe cognitive disabilities. However, for this condition of "mental retardation" as well as others, it is not possible accurately to assess the influence of such factors as coercion, political motiviations, and naivete, in the determination of our, and these other, prevalence estimates.

The ostensible purpose for defining groups, labeling individuals, and developing incidence and prevalence estimates is to serve better those individuals defined and labeled. If labeling does not lead to services, and it often doesn't, it reduces what might have been a helpful procedure to a pejorative and detrimental act.

TABLE II

Estimated Needs for Special Community and Residential Services for Children and Adults in a Modal Region of 500,000 Population

Category	Percent of Total Population in Categories	Estimated Number in Categories
I. Major Categories		
a. Percent of total population needing special services due to their mental retardation.	1% of total population: .75% EMR; .20% TMR; .05 SMR.	5,000
b. Percent of total population needing special services due to their behavioral disturbances.	1% of total population: .50% Severely ED or SM; .50% moderately or mildly ED or SM.	5,000
c. Percent of total population needing special services due to moderate and severe sensory and/or physical disorders.	1% of total population: including .03% blind, .08% deaf; .14 severely sensory and/or PH; remainder partially disabled.	5,000
II. Sub-Categories		
a. Mental Retardation		
1. Individuals in need of special programs in public school at any one time.	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school years.	50% of entire mentally retarded population	2,500
3. Individuals in need of residential placement, at any one time, with alternative programs available.	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and pre-school programs	5% of known mentally retarded population	250
(b) Day Care Programs	5% of known mentally retarded population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Day Activities	10% of known mentally retarded population	500

TABLE II (Continued)

Category	Percent of Total Population in Categories	Estimated Number in Categories
II. Sub-Categories		
b. Behavioral Disturbances		
1. Individuals in need of special programs in public school at any one time.	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school yerrs.	50% of entire emotionally disturbed population	2,500
3. Individuals in need of residential placement, at any one time, with alternative programs available.	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and preschool programs	5% of known emotionally disturbed population	250
(b) Day Care Programs	5% of known emotionally disturbed population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Activities	10% of known emotionally disturbed population	500
c. Sensory and/or Physical Disorders		
1. Individuals in need of special programs in public school at any one time	1% of total school population (125,000)	1,250
2. Individuals in need of only minimum services other than special programs during school years.	50% of entire sensory and physically handicapped	2,550
3. Individuals in need of residential placement, at any one time, with alternative programs available	.1% of total population	500
4. Individuals requiring other services		
(a) Nursery and preschool programs	5% of known sensory and physically handicapped population	250

TABLE II (Continued)

Category	Percent of Total Population in Categories	Estimated Number in Categories
II. Sub-Categories		
c. Sensory and/or Physical Disorders		
4. Individuals requiring other services		
(b) Day Care Programs	5% of known sensory and physically handicapped population	250
(c) Sheltered Workshop Activities, Vocational Training, and Adult Day Activities	10% of known sensory and physically handicapped population	500

Therefore, I too should at least present some estimates of needs and types of programs that may serve these special populations. I include in these estimates (Table II) not only those whom we label "mentally retarded" but people who have other handicaps. The overlapping nature of these disabilities and the frequent occurrence of multiple handicaps among the moderately and severely disabled dictate a more global assessment of needs than what a single categorical approach could provide. Given all of the aforementioned caveats, and the additional one that I think I know a good deal more about the prevalence and incidence of mental retardation than about other disabilities, I nevertheless believe that these estimates may be helpful to those who have been forced to design programs without even the grossest notions of how many people they should plan for and what those people may need during their developmental and adult years.

In a perverse and ironic manner, we may be fortunate that needs seem always to be bottomless, endless and never met. That is, we haven't suffered from an overabundance of services for so-called handicapped people. On the other hand, especially with limited resources—which we will probably always have to confront—it may be useful strategically to place those resources where they can do the greatest good for the greatest number.

While many experts in the field of mental retardation have argued that, for example, 16 percent or 3 percent or 5 percent or 2 percent (AAMD) of the population are mentally retarded, or "psychometrically mentally retarded," or own study[34] indicates that a 1 percent estimate is more valuable for program planning and development. Similarly, estimates as high as 20, 30, or 40 percent in the relatively new category, "Specific Learning Disabilities," are provocative, certainly, but do not appear to be helpful in program planning. Further, prevalence estimates of various types of handicapped children (not including the new general category, "Learning Disabilities") conclude that approximately 10 percent of all school age children are "handicapped." Unfortunately, there are problems with this estimate for the same reasons that epidemiological data on mental retardation have never provided satisfactory guidance for program planning.

The studies that have been completed indicate that there are important differences between what we might call "administrative disability" and "objective disability." As mentioned, a clear example of this dichotomy is the discrepancy between psychometric mental retardation (at least two percent of the total population) and administratively designated (or known) mental retardation (approximately one percent of the total population). Therefore, taking these factors and their resultant problems into consideration, I believe it is reasonable to consider using population estimates that are based on available studies of known cases in the various disability categories.

From our own demographic studies of mental retardation, our evaluation of the epidemiologic literature in the field, and from a careful analysis of the data obtained from both our Head Start questionnaire survey and our observational studies of selected Head Start programs, we estimate that one percent of the total population (incidence) need special services because of their mental retardation, another one percent require it because of behavioral disturbances, and another one percent because of moderate and severe sensory and/or physical disorders (see Table II). We would not include the so-called speech-impaired in such designations; nor would we include the so-called learning disabled.

We believe it is not in the best interests of either the children or the programs to label children with mild disabilities, who could otherwise be adequately dealt with in ordinary classes, as "handicapped," "retarded," "speech-impaired," etc. We believe it is in the interest of both the children who have been so labeled until now and those others who are now denied a normal interaction with them, to reserve the categories of handicap only for those who have such severe and moderate needs where they will not be able to be served adequately in ordinary classes under ordinary conditions.

For that group with such special needs, we estimate that there is no more than a three percent incidence across populations and age categories, and possibly, a four percent and no more than five percent prevalence during the preschool and school years. Therefore, mild speech impairment, as mild retardation or disturbance, could not be considered a handicap requiring special attention in the traditional sense. Those children with mild disabilities should be served within the context of regular school settings. Those with severe or moderate speech impairments will be found to have general language disabilities and, more probably than not, learning, behavioral, sensory, or physical disorders.

Obviously, the above recommendations will not solve all of the difficulties inherent in estimating the incidence and prevalence of conditions that are grounded more in political-metaphorical issues than in scientific ones. However, at least in some modest manner, we may be able to reduce the harmful effects of unnecessary labelling and the resultant stigma to many children and their families. We may also move from a disease-oriented planning model to a developmental model, one that seriously considers the benefits of integration and decategorization of both children and programs, one that is committed to the concept that people are educable, that development is a function of not only endowment but training and opportunity and encouragement.

Research

Like the emperor's clothes, for many years research concerned with disabled populations proceeded along experimental, quasi-experimental and other traditional lines of investigation. And, in spite of the null hypothesis consistently obtaining, in spite of our inability either to learn very much or to help very much—not necessarily related matters—we continued to apply traditional approaches to the study of very complex field problems, invariably with very unsatisfactory results. The problem of relevancy of research methodology has been particularly troublesome in the broad field of research on children with special needs.[35]

We need to develop research strategies that are in harmony with discovering and evaluating what actually occurs in natural settings, be they classrooms, clinics, institutions, homes or neighborhoods. Possibly, this orientation to research offers a solution to what Blackman[36] described as the serious and ambivalent dichotomy between those who prefer experimentation as the method of proof and those who view education essentially as an art form, one which could lose its color and vitality if the movement to fractionate the teacher-pupil interaction achieves its apparent goal.

In numerous ways, individuals function differently. Research attempts to record these ways and to explain the way. For some researchers, description is an end in itself. However, the history of social science has, at least, one certainty about it; description always leads from and to something. There is no "unbiased description." For example, when several groups are given I.Q. tests, almost invariably they will have different averages. Are those objectively derived differences? We believe not. A good deal went into the development of the I.Q. test, selection of items, and procedures for administering the test. The testing format is, itself, a very special structure for communication. Tests are validated in specific ways using specific criteria. They are developed to do something. The narrower the something is, the easier it is to validate the test; however, the test becomes more biased when used with other groups at other times.

We often talk about variability. What makes the great difference? Is it heredity or environment? Is it school or home? Latin or home economics? Discipline or therapy? If a child has a problem, what (or who) had the most to do with it? What is the main, most significant, most pervasive cause? What is the best, very best, way of undoing the problem? Does the answer to the first question (cause) lead to the answer to the second (Undoing)? Does what is wrong indicate what should be done?

Eventually the question is: What should we do? And, how do we obtain that answer? Does it depend on who does it? or where it is done? or how much time there is? It is wishful thinking to expect that there is a clear relationship between what exists, why it exists, and what to do about it. Useful reductions are impossible, at least in the usual sense. Prescriptive education is a reduction. Therapeutic education is a reduction. Montessori, Frostig, Kephart, Cruickshank, Bereiter, A. S. Neill all offer reductions. To a degree, what we say about reductions is a reduction; hence the tautology of it all and, if we're not careful, the self-inflicted delusionary trap. In this paper, we attempt to discuss the potential dangers of any reduction—be it "theirs" or ours. Reductionists say this is what to do with children who present or behave in this manner. Whatever this is, there is the assumption that this can be identified, described and distinguished from something other.

What contributes to difference? Some children are poor, come from families who have inadequate housing, food, medical services, space—are crowded into cities (or rurally separated)—and they do not do well in school! Or on tests! Or on the 'cello! Often, they are migrant or immigrants. And they do not speak Standard English. They are different. They do not fit well.

A lot of confusion exists about what people should do, how they should do it, and when it should be done. Who is to judge? Are the judges' values my values? Or yours? How can it all be put together: poverty, delinquency, migration, retardation, language, values, anthropological, epistemological? Some individuals in some groups do not fit. The first problem is to decide about fit: individuals who do not fit, groups that do not fit, or individuals who do not fit groups that do not fit.

There are several differences to being an individual who does not fit (or is not well matched) rather than being in a group that does not fit (or is not matched). The new field of learning disabilities has epitomized the Individual-no-match.[37] Find out what is wrong, then treat it. The patient will subsequently get better. Mental retardation has always been in the Individual-no-match category. Unfortunately, this was a strategic error and interferes with progress in our field. For example, the Black population of the United States may be an illustration of an Individual-no-match category that did not begin to move out of a repressive society until they developed Black Power and Pride—i.e., until they assumed a Group-no-fit strategy.

The literature in our field indicates that the preponderance of published research is experimental. Most studies of teaching have used traditional designs, whether they were efficacy studies, follow-up studies of children in special and regular classes, studies of different methodological approaches, or studies of different curriculum approaches.

We believe there are more appropriate ways to study teaching-learning in classroom, clinic, or tutorial situtations. However, it is well known that researchers engage not in what they want to do but what they are able to do, not in what is important but what is possible, not in what is risky but what is safe and gives assurance of completion. People do what can be supported and most of us engage ourselves in activities that are comfortable and appreciated by others. Possibly, the most accurate judgement we can make about research with disabled populations is that this is what the people in the field want or, possibly, there is not anything else known that they can or wish to subsitute for their current mode of activity.

We conclude here that:

1. There is nothing inherent in disability to produce handicap (i.e., a belief in one's incompetency). Further it is not the primary responsibility of the behavioral sciences to determine the validity of the aforementioned statement, but to make it valid. We have supported far too many studies purporting to demonstrate differences between groups or the disorders of one child in contrast with another. All these years we should have promoted and encouraged research that sought to make it come true that a child would learn after participation in a special program or curriculum.

2. The above leads directly to a second recommendation, viz., the study of particular methods, for the purpose of demonstrating their

efficacy, is rather fruitless and whatever is demonstrated will eventually be contradicted by subsequent research. Such "all or nothing" studies of methodologies prove little. By "all or nothing" we mean studies that compare the efficacy of one method with that of another or compare the superiority of one type of individual with that of another.

Or, as Campbell and Stanley incisively concluded, ". . . we must increase our time perspective, and recognize that continuous, multiple experimentation is more typical of science than once-and-for-all definitive experiments . . . we should not expect that 'crucial experiments' which pit opposing theories will be likely to have clear-cut outcomes."[38]

On the other hand, we are not ready to suggest that there is nothing but uniqueness in an educational setting. There must be possibilities for building generalizations for, if "knowledge" is an objective, we must be concerned with degrees of nonuniqueness or lawfulness. Unfortunately, as we stated above, the numerous dimensions of child-teacher interactions have been neglected and, consequently, hardly understood.

As methods do not exist outside of psychological-educational setting, and as they are implemented by unique groups of human beings, only a naive researcher could conclude that the demonstrated superiority of his method has direct and specific transferability to other educational settings. Our research preference is to study children and how they change in different educational environments. We believe it is more defensible, and will make a greater difference, to generalize about children interacting with each other and with adults in situations than it is to generalize about procedures. It is from evaluations of varieties of methods, with varieties of children in more or less formal and informal settings, utilizing teachers with heterogeneous backgrounds, that hypotheses will be generated that will lead to viable theories concerning human development and learning. It appears to us that, with this kind of strategy, theory construction shifts from methodological concerns to those involving human interactive concerns. However, even this isn't "everything." True enough, there is value in theory for its own sake, but we should not expect that there always will be additional practical value, that the theory be helpful to the retarded, or the disadvantaged, or whomever. For instance, although nuclear physics may have much to say about tables, should a nuclear scientist attempt to instruct the carpenter? Is it possible that much of our research in mental retardation is akin to a nuclear scientist trying to learn to make dovetail joints in a cyclotron? Or, to offer another analogy, here is a favorite "likely story" of a colleague in philosophy.

She: "Look, dear, that's our star."

He: "That's not a star. That's a planet."

There are situations in which science and research is neither useful nor appropriate.

We have attempted to discuss a relatively unpopular position among researchers, a position that assumes that human research should not be an activity that is separated from life or from values and prejudices about people. Further, we believe that it is impossible for the researcher to separate completely his beliefs from his research activities, even if he makes deliberate efforts in that direction. Therefore, research with so-called disabled persons should proceed, first, from a statement of values, then to an intervention and evaluation, with careful efforts to explicate the former, rather than to submerge it in an unsatisfactory and contrived research design.

What is our bias? Put as simply as possible, we believe that capacity is a function of practice and training (e.g., intelligence is educable). And, as we have said earlier, it is a task of researchers, as it is the task of all clinicians, to validate the bias. In the ultimate sense, this is our central mission.

Business and Finance

The newly emerging literature on the economics of mental retardation is important and was long awaited by the professional leadership, the political community, and the consumers. I wish to address myself in this section to aspects of "business" that are rarely, if ever, discussed in professional publications or, for that matter, in polite society. And I believe what I am about to discuss is somewhat important for those struggling to understand why we make the decisions we make and why past experiences and data are incidental to such decision-making.

For one year, during a leave of absence from my university, I was the Commonwealth of Massachusetts Commissioner for mental retardation programs for the Department of Mental Health. At least theoretically, if not always pragmatically, I was responsible for the conduct of all of the Commonwealth's state institutions for the mentally retarded, and all of the Department's community educational and clinical programs for those people designated as mentally retarded who, for one reason or another, "escaped" institutionalization.[39]

I will begin with the conclusion. Mental retardation is big business. It is very big business. One research group reported recently that there are 2,800,000 mentally retarded youth in the United States and that government agencies expend $2.8 billion annually to serve them.[40] Its dollar volume does not approach expenditures for mental health. But how many businesses do? Let's look at some of the "evidence."

I have observed in several states that the largest purchaser of buildings in a state is the state itself. Further, within state governments, departments of mental health are oftentimes the most consistently largest purchasers of buildings. Even in the wake of a national clamor to invest our resources in programs, not real estate or buildings, giant steam shovels are ripping large chunks of land across this country, harbingers for institutional monstrosities, that must always disillusion some and totally defeat others.

New York State, in the wake of public scandals and anguished outcries, after promises to do better and differently, continues to build large—although not as large as Willowbrook and Letchworth—ugly institutions at costs of $40,000 to $60,000, and more, per bed. Within the past few years, the state has been engaged in a half-billion dollar institutional building program in mental retardation. Why? Answers aren't easy and those that are readily available may be potentially libelous. However, even a school boy can deduce that six percent of a half-billion dollars—architects' fees—is a great deal of money. Even the most unsophisticated citizen will appreciate the importance major construction programs have for contractors, suppliers, land developers, the unions and, especially, the banks who together will "earn" a half billion dollars on this mental retardation construction. Even the most naive and apolitical citizen will remember that, when an official in a high federal government position was forced to resign for kickbacks taken while he was once governor, those who provided the "kick" and the "vigorish" were all either contractors, land developers, or architects. How can we terminate institutional building programs when, in many states, they are literally the source for political party, and even private, payoffs and patronage?

Let's look at operating expenditures. In New York State during the 1974 fiscal year, the mental retardation division in the State Department of Mental Hygiene was allocated a budget of $235 million. Of that amount, only $2 million was earmarked for community programs. Why? Well, one answer is that buildings, the staffs, and the inmates are there; so, the resources must go to the institutions. To a degree, this is a reasonable explanation. But why do we continue to use outmoded, sometimes disgraceful, always less than desirable or logical institutional settings?

First, there are unions, who find it convenient to have their members together in one facility; dispersal to many community programs may impair a union's strength and effectiveness. Secondly, there are administrators and supervisors who, similarly, find it compatible to have their staffs working in centralized facilities; dispersal of inmates leads to the dispersal of staff and the realization that neither all of the administrators nor all of the direct care personnel are necessary. Certainly, it would be difficult for an institutional superintendent to speak any longer about "his institution" if the institutional population were evacuated and resettled in integrated communities. Thirdly, if there were no institutions there would be no million dollar laundry contracts, multimillion dollar food contracts, milk contracts, ice cream contracts, automobile contracts, service contracts, utilities contracts, even funeral contracts. Certainly, as matter is neither created nor destroyed, people must eat and soiled clothes must be washed. However, it's not the same, especially for larger influential businesses, to comtemplate one contract for a million dollars as it is to contemplate competing for a thousand contracts for a thousand dollars each, or thousands of purchases by free citizens.

There are analogies in public education, contrasting segregated schools with integrated programs. There are analogies in comparing specialized clinics with generic clinics. As the Blacks learned, as the Jews learned, as the Indians are now learning, segregation, bigotry, and prejudice can be big business. In our field, considering our modest number of clients and our relative low priority in the scheme of things, mental retardation is big business, and it's big essentially because it's segregated and monolithic and, therefore, controllable. Either we must find a way to remove the overly attractive rewards that some people seek and find in this business or we must desegregate our programs and clients;

otherwise little will change. Rhetoric, promises, or even good intentions, will not alone discourage half-billion dollar state building programs or $50 million operating budgets for places like the Willowbrook Developmental Center. Either we demand a total moratorium on all construction, and quickly and efficiently remove other fiscal incentives, or we deal with this problem from the other end, reorder priorities (but, remember the "Year of the Child") and evacuate institutions and special segregated schools; otherwise mental retardation will continue to be big business—and great despair for those who truly want to serve others, and for those who must be served.

Decision-Making

Subsequent to my year as an "executive" in mental retardation administration, I wrote a book about that experience. Chapter Ten, "Life with the Decision-Makers," dealt with that aspect of government concerned with insiders and outsiders, accountability, the civil service, relationships with the executive and legislative branches, and how people "hide" in government. Having nothing new to say on the matter, I will repeat here what I wrote then under the heading of "Decision-Making and Accountability":

"Few people are forced to make decisions because few people are accountable for specific programs or activities.

"Obviously, those people who are accountable for specific activities must make decisions. How are these decisions made? A better question might be, 'What causes an individual to make one decision rather than another?' For many months my experiences at 15 Ashburton Place puzzled me because I was completely unable to 'read' the System vis-a-vis decision-making. For example, several of what I considered to be very reasonable requests were denied by various business offices without explanation or apparent reason. Other requests were ignored. Still others were quickly and categorically honored to our complete satisfaction. There was no apparent logic to these responses. It seemed as if some mad table of random numbers was at work here, approving one thing, denying another, and ignoring the third. It must be admitted that in each instance when I did require an explanation for a decision, there was some law or regulation or policy that seemed to lend credibility and wisdom to the decision. However, on other occasions, similar requests—in equal violation of the regulation or policy—would be granted. All one can do is speculate about the basis for decision-making at 15 Ashburton Place—as, obviously, one can't read the decision-maker's mind and there seems no logical pattern to his activities. My speculations have led me to three insecure and tentative conclusions: (1) It is thought much simpler and less perilous to make no decision, or to decide negatively, than to decide positively. (2) The System make it more satisfying to decide negatively than to decide positively. (3) The process of working with laws, regulations, and policies encourages their utilization to prohibit activities and developments rather than to promulgate such activities and developments.

"Because so few people have accountability and, consequently, so few people may make a final decision about a matter, most requests for one thing or another pass through several hands if, eventually, they are to be approved. With the exception of upper echelon business office personnel, there are few so-called 'middle management' professionals who make final positive decisions. In innumerable situations, these individuals may make final negative decisions, i.e., they have the authority to ignore or deny a request but do not have the authority (or do not believe they have the the authority) to approve it. Further, to approve a request for funds, personnel, a specific program, a transfer of personnel, or some other change from the 'usual' is to—in effect—approve the wisdom of that action and certify the legality of that action. To ignore or deny the request permits the decision-maker freedom from accountability for his decision, yet permits him to make a decision. Inasmuch as the laws, the regulations, and the policies are not always without ambiguity and discrepancies and are, in fact, frequently open to multiple interpretations, one can more easily find his safety in that part of the law or policy that permits the decision-maker to ignore or deny than in that part that permits him to approve and, thus, requires him to stand behind his decision.

"Whatever the central cause or causes are, there are many more negative than positive decisions made at 15 Ashburton Place.

"As in the System the decision-maker rarely has the authority to approve, he is caught continuously in the frustration of 'shuffling papers' from his desk to a higher desk, and of getting entangled in the red tape, bureaucracy, and inertia that are companion to such activities. It appears to be so much 'cleaner,' manly and authoritative to deny a request than to involve oneself in the frustrations implicit in passing on this request to higher authority. It is, therefore, not difficult to surmise that there are negative decisions made whose sole purpose is to 'satisfy' the decision-maker. And further, this narcissistic behavior is understandable, if not completely forgivable, in light of the untenable position most decision-makers are forced into. That is to say, most decision-makers may make no decision or a 'no' decision but very infrequently have the option to make a positive decision. It is this set of circumstances that, I believe, causes more unhappiness and job dissatisfaction, frustration, and mutual ill will at 15 Ashburton Place than any other—including such problems as salaries, working conditions, job pensions, and the enormity and complexity of the departmental mission.

"Lastly, the innumerable frustrations and roadblocks one encounters in the decision-making process must eventually wear down a man's will to move things along in the proper direction and to make the proper decisions. From my limited observations, it appears that the Commonwealth laws and the Departmental regulations and policies are used—not to facilitate or permit positive decisions to be made—but to determine if it is legally possible or departmentally justifiable if a positive decision should be made. Essentially, and I know there is a fine line of distinction here between what may and may not be legal or prudent, the departmental modus operandi is first, to find something in the laws or regulations or policies that prohibits one from doing something rather than view these statutes for the purpose of finding justification for doing something. I have observed that departmental officials do not comb the statutes to find new opportunities to offer services and facilities, but they do comb the statutes for any prohibitions or incumbrances to a request that has been presented to them. Laws and regulations and policies being what they are—and Massachusetts being a Commonwealth long in the mental health business—it is often very difficult to 'get something done' in the face of governmental and departmental restrictions, precedents, and inertia. I do not wish to communicate the impression that I am advocating flagrant violation of laws or regulations. Nor do I believe it unwise to proceed carefully and thoughtfully before decisions are made that affect the lives of patients or the careers of personnel. However, if a System is based on convictions and standards and precedents that make it easier, less perilous, and more satisfying to make negative decisions than to make positive decisions, to the degree that this assumption is true, laws, regulations, and policies will be interpreted in the light of their prohibitionary powers rather than in the light of their enabling powers."[41]

Concepts of Mental Retardation

Mental retardation is not something that can be simply and scientifically defined, discussed, dissected, applied or studied. Mental retardation is related to our very understanding of humanity, of human potential, of educability, of equality, of rights and privileges, of everything we are and everything that relates to us. Asking someone to comprehend a concept of mental retardation is akin to asking him to comprehend a concept of spirituality or decadence, beauty or ugliness, strength or weakness, good people or bad people. Mental retardation can't be encapsulated and "pictured" by I.S. parameters, or even etiological descriptions, or behavioral assessments. It must always be anchored to other people, a community, values, expectations, and hopes. Therefore, the epidemiology of mental retardation can only be discussed in a psychological-social-political-economic context. Further, the economic factor, or any other factor or problem, can be appreciated only in this same context. Unfortunately, we have neither a manual on terminology and classification nor a curriculum that will permit us to shortcut this conceptual process.

Also, unfortunately, one's concept of mental retardation may impair seriously otherwise good judgment. Prejudices concerning those whom society calls "mentally retarded" may cause even the most distinguished and wise among us to do thoughtless things and issue silly pronouncements.

Reform or Revolution

I've asked the question many times, yet there is no answer for me. Possibly, there is no answer because I'm not pleased with the answers I see. I cannot tolerate the invidious comparison between the promises made and the institutions created. And, what were the promises that our field was to keep? What did the institution, the special education program, the community mental health-mental retardation movement contribute? We have been faithful, some have worked unselfishly, some have raised large sums of money, many have supported humanistic precepts and philosophies on behalf of people with special needs. What good was to come of all of this? The hope then, and remaining today, was that people would gain strength, would deepen their optimism and faith in the human ethos, would develop more genuine concern for our brethren, would eventually have the wisdom to believe that all human beings are equally valuable, and that our work is not to judge who can or can't change but to fulfill the promise that all people can change, that each person can learn. The promises made were to coalesce around the demonstration, especially to those of us most intimately involved, that society is each person, not multiplied but singular, each person unique and valuable.

Yet, what have we created? We find that, in instutitions and in many special schools, both the caretakers and the clients victimize and are victims. In the institution, and in many special school programs, there are not sufficient options for children, for families and, equally important, for staffs. In plain fact, the research available confirms the shambles that too many special programs and facilities are.

Yet, in spite of powerful critical reports on institutional life,[42] and the scientifically questionable but numerous reports on special class life,[43] we continue to build more and more institutions and pass more and more mandatory rather than permissive special education laws—regardless of the well known fact that we have yet to demonstrate either the efficacy or moral rectitude in continuing, much less encouraging, those segregated programs. To turn to an earlier theme, such proliferation on the basis of trivial evidence is but another illustration of the monolithic influence.

We have made os many concessions, we have so bent the data to suit our ignorances and confusions, we are so anxious to please the people, that we lie to spare them the anxiety we feel because of what we have created. I'm expecting that, at any time now, somebody will propose a new concept, a remodeling of the old French triage system for sorting out and treating battlefield casualties. However, the neo-triage model will deal, not with the militarily wounded, but with those whom bad luck, accident, and society inflict their insults upon. I'm expecting to read someday an "erudite" paper advising us to set aside the hopeless, for their very designations demand we should not waste time with them; and, we might best benignly neglect those who will probably do as well without us, those who puzzle us, or those whose problems—although real—do not fully incapacitate them; and, consequently, we should reserve our resources and energies for those who most need our help. Possibly, in war, triage is a valid concept; where some will live and some will die, and resources are particularly scarce, the whole thing—ghoulish as it may be—makes at least a little sense. However, when the new triage is trotted out, will there be anyone to say, "But, we are not at war"? And, will there be anyone else to say, "no, we are not at war. Yet, we should have been. It was always a war, but most of us thought of it as merely a debate."

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Biography

BURTON BLATT was born in 1927. He studied at New York University, the Teachers College at Columbia University, and at Pennsylvania State University, where he received his doctorate in special education. During World War II, he served with the United States Navy in the Phillipine Islands.

He has taught special classes for the mentally retarded in New York, and held a teaching position at Southern Connecticut State College from 1956 to 1961. From 1961 to 1969 he was professor and chairman of the special education department at Boston University.

Since 1969 he has been the centennial professor and director of division of special education and rehabilitation and the center on human policy at Syracuse University. Dr. Blatt has published numerous articles and books on a wide range of subjects.

10. The Uses of Courts and of Lawyers

Thomas K. Gilhool

The Setting

We are living and working, happily, in an era in which assumptions about the nature of persons called "retarded"—and a wide variety of other persons called black, women, poor, elderly, Asian—are changing. Assumptions about human nature are not easily uncovered, let alone changed, because they can be deeply taken for granted. Once we stumble into awareness, however, we face an opportunity (maybe a short-lived opportunity) to render a new understanding, itself taken for granted. Erving Goffman writes: "During periods of marked social change, when individuals acquire rights or lose them, attention is directed to properties of individuals which will soon become defined as simply human."[1]

Changing assumptions, and changing facts as well,[2] invariably give rise to claims of right. And, inevitably, claims of right will implicate the law. We are after all, or we are struggling to become, a constitutional society. Notions of "person," and changing notions of who are persons and who are not, and who are not in what particulars, will, therefore, be expressed formally in the fabric of our laws and those notions more or less imposed by the laws.[3] And if the law is implicated, so are the courts. For the courts are entrusted with the generation of claims of right and with their authoritative adjudication. To be sure, these functions are not confined to the courts alone. Claims of right may be validated by negotiation and by legislation and, still more informally, by widespread practice and custom. But the courts have a special place in working out the claims of rights of persons subject to prejudice, which may distort the workings of negotiation and legislation and which may have corrupted custom entirely.[4]

"Independence and self-confidence, the feeling of creativity . . . , lives of high spirits rather than hushed, suffocating silence," the Supreme Court wrote in *Papachristou v. City of Jacksonville*,[5] is the promise of the Constitution of the United States to its citizens. The question is: how can we use the courts, the law, and lawyers, and how can we organize ourselves in their use most quickly and surely to generalize new notions of rights of retarded persons—and indeed of all persons who are different—and do so not only in symbolic terms but also in reality?

The Uses of the Courts

The question is: of what use(s) are the courts in declaring rights, in fashioning and enforcing remedies, and in securing change itself? The answer is more complex than sometimes appears: Courts may establish rights, remedies, and change directly, and especially often will they define and declare rights, but their most important use is instrumental. The courts' declarations, and the forum they provide, affect the balance of forces in other political arenas to secure remedy and change. As one commentator puts it, "The declaration of rights is ordinarily a prelude to a political struggle."[6] The courts are not a magically different instrument of change; like each of the other instruments there are tasks and times to which they are especially well fitted. But in no case will singleminded use of the courts be effective. The use of litigation along with lobbying and bargaining promises to be effective. Our task is to use the courts not only for their own yield, but also for their effect in other arenas.

The litany of rights declared in recent litigation by retarded citizens is familiar. The right to appropriate education. The right to treatment. The right to due process. The right to a minimum wage. The right to employment. The right of access to public transportation. The right to reside in the community. The right to services in the community. In sum, the right to be different and to have that difference accommodated.

Those declarations reflect the beginnings of the application to retarded citizens of basic constitutiona notions. Taking Plato's ideal Commonwealth as his counterpoint, Mr. Justice McReynolds, writing for the Supreme Court in *Meyer v. Nebraska*,[7] expressed them as follows:

"For the welfare of his Ideal Commonwealth, Plato suggested a law which would provide: 'That the wives of our guardians are to be common, and no parent is to know his own child, nor any child his parent . . . The proper officers will take the offspring of the good parents to the pen or fold, and . . . will deposit them with certain nurses . . . but the offspring of the inferior, or of the better when they chance to be deformed, will be put away in some mysterious, unknown place, as they should be.'

"Although such measures have been deliberately approved by men of great genius, their ideas touching the relation between individual and State were wholly different from those upon which our institutions rest; and it hardly will be affirmed that any Legislature could impose such restrictions upon the people of a State without doing violence to both the letter and spirit of the Constitution."

In *Meyer* v. *Nebraska*,[8] and elsewhere in the fabric of American constitutional law, five norms are clear. First, liberty. Citizens are to be freed from stereotyping. Not only is the state not to poach upon citizens but the state is to protect them in pursuit and realization of their capacities. Second, equality. "Inferior"—"superior" distinctions are disfavored. It is not that unequally situated persons are to be treated equally. Justice Frankfurter said that would be a travesty of equality.[9] Rather, citizens, each of them, are to be accorded a functional equality, and none of them are to be set apart. Which is to suggest the third norm, integration. Or what retardation professionals have come to call "normalization." Integration, not to deny difference, but to create or to allow, to protect, space for difference within society. Indeed, integration to clebrate difference. Hence, the fourth and fifth of the constitutional norms: Individuation in the state's address of its citizens. And the reservation to each citizen of choice about who he is and who he shall become.

This is not the place to parse these norms doctrinally, nor is it the place to weigh precisely the uncertainties in their application in any particular case in any particular court at any particular times.[10] Suffice it to say, it is constitutional values we seek. As constitutional values they are, almost by definition, also values widely held in the society at large.

The question then is what functions may the courts serve in giving flesh to the word[11] and fulfillment to the promise these norms embody.

The uses of the courts and of litigation are at least four. One, to secure the authoritative declaration of rights, to change or to refine the rules which formally govern conduct. Two, to create new forums and to structure new relationships wherein declared rights may be enforced and where new rights may be declared. Three, to bring forcefully to the attention of legislators, executives, bureaucrats and other public and private decision-makers and to the attention of the citizenry at large, certain facts or authoritative characterizations which have not had great visibility or salience before. And four, like each of the other modes of petitioning the government for redress of grievances, litigation may abe used by a citizen to express hi(r)self, to tell others who (s)he is, or to redefine hi(r) notion of hi(r)self or the notions others have of hi(r).

To Change the Rules

The right to education cases will illustrate.[12] The rules were changed in at least five ways. By court order, the new rules were: first, zero-reject education, the inclusion of all children, no matter how handicapped, in free public education. Second, education appropriate to each child's needs and capacities. Third, (an initial step toward an operational definition of the standard of "appropriate" education) written, individually prescribed plans for the education of each handicapped child. Fourth, the delivery of education in as integrated a setting as possible (a strong presumption that mainstreaming is the appropriate education). Fifth, the opportunity for a full hearing on the appropriateness question before assignment to special education, and thereafter before any change in educational assignment and periodically (annually, most often) in the course of the child's schooling.

To Create New Forums

Apart from the courts' usual power of enforcement (contempt is the chief formal power), the right to education cases established several new forums—some temporary and some permanent—and otherwise restructured the relationships among the parties (and non-parties as well). They provided new formal (and informal) mechanisms to give further operational definition to the children's newly declared rights, and to enforce them and perhaps to create new rights. Four such new structures have arisen from these cases.

First, a due process hearing is now available to each child to determine whether hi(r) educational assignment is appropriate. Typically, the hearing is to be held by the Secretary of Education (or hearing examiners designated by and acting for hi(r)). The child is entitled to access to all school records before the hearing, to an independent evaluation of hi(r) educational needs and capacitities and the appropriateness of hi(r) educational program, to representation at the hearing by an Association for Retarded Citizens advocate, a lawyer, or any other person of hi(r) choosing, to the opportunity to present evidence and to cross-examine school district witnesses. Thus, for the child and hi(r) parents—if the resources and skills necessary to manage the hearings are adequately distributed and accessible to them—the hearings may provide the means to secure in fact the appropriate, integrated education the courts have declared is legally their right.[13] In addition to restructuring the relationship between parent/child and the school district, the due process hearings may alter relationships within the education bureaucracy. For example, the power of teachers and psychologist as against administrators, local and state, may change, given the opportunity the teacher now has in the due process hearing to present at the highest level of the state education bureaucracy hi(r) best professional judgment of what is required to provide the appropriate education for a particular child and the opportunity to make claims for recourses necessary to deliver that education.

Second, under aegis of court orders, state and local task forces (one for each county or intermediate unit) are forming. Each is composed of Association for Retarded Citizens and other handicapped organization representatives, the school districts, and the county mental retardation agency, and empowered to oversee the planning for and the implementation of the courts' declarations.

In one state (Pennsylvania), at least, these task forces have been made permanent by state regulation. The very existence of these task forces, to say nothing of the possibility of a network of links and strategies among Association for Retarded Citizens advocates on each county task force and on the state task force, may alter the balance of forces bearing on educational policy and the delivery of education. The relationship between Association for Retarded Citizens and the other parties in the task force may be further defined and detailed formally in the direction of a duty "to bargain in good faith." [14] It may take on the formal characteristics of the statutorily required Developmental Disabilities Councils,[15] or Title I parent groups,[16] or of any of the range of relationships defined in the Housing Acts for urban renewal, housing code enforcement, and community development.[17]

The right to treatment cases—notably *Wyatt v. Stickney*[18]—create Human Right Committees, sharply defined neither as forums for hearings nor as forums for collective bargaining, but which hold prospect to become either or both.

The appointment of Masters to oversee the implementation of court orders in the right to education cases as in desegregation and corporate reorganization cases may provide for the short life of the Masters' term a new forum in which relationship between the parties are altered. And, of course, during the litigation itself, the very dependency of the litigation may change the power relationship among the parties and yield bargaining on quite different terms.

To Focus Attention

In addition to creating new rules and new forums, litigation and the courts may be used to bring fact hitherto invisible to the attention of legislatures, executives, bureaucrats, and other private and public decision-makers and of the public at large, and otherwise to change their understanding of the matters at issue and the people who have put them at issue.

It is true that "rights are declared as absolutes, but they ripple out into the world in an exceedingly contingent fashion." [19] It is true, as a consequence of this and of the analysis offered here, that a court's declaration of rights is only one event in a political struggle. But that does not mean that the declaration of rights exhausts the uses of the courts. Chief Justice Warren wrote:

> "Whenever the Congress discerns some defect in our society, within its constitutional limits it may reach out for solution. If it cannot achieve consensus on . . . a complete solution, it may compromise for a half or a quarter loaf or even postpone its action . . . When the Court determines the relevant facts, it must apply the legal principles applicable to them. The judge is not justified in parceling out a portion of the rights established by a statute or the Constitution . . . The judicial process, therefore, might well be described as 'the process of principle,' as distinguished from 'the art of the possible.' " [20]

But the court, nonetheless, may have significant effect in the arena of compromise and on the limits of the possible. The judges' function, Alexander Bickel argued, is to call attention to constitutional values, to demonstrate the evils present in some "political" compromises, to move the other political processes "off the dime," and thus to alter the vector of political bargaining.[21]

Attention may be secured just by being in court, even short of the courts' authoritative findings. When plaintiffs file in any case of public interest, they can expect to be featured, as cases presenting the claim of retarded citizens invariably are, in the printed media. When authorities like Gunnar Dybwad and Ignacy Goldberg come to court to testify to the fact that all retarded children are educable, the electronic media will broadcast those facts from the courthouse steps. When the courts enter authoritative findings on the educability and employability of all, they are broadcast and the interrelations between the courts and the other political processes—and the opportunity of using all the processes—become clear.

Consider Section 503 of the Rehabilitation Act of 1973. Undoubtedly, apart from the right to education and the right to treatment cases (or better put, in conjunction with them), this is the recent development with the most revolutionary potential for the quality of life of handicapped citizens. Section 503, the first legislatively enacted affirmative action requirement for employment of handicapped persons in the country's history, requires that virtually every government contractor (any with a contract larger than $2500) "shall take affirmative action to employ and advance in employment qualified handicapped individuals."[22] This requirement must mean not only nondiscrimination and affirmative efforts to hire the handicapped, but the fitting of work settings and job tasks to the handicapped. As the Supreme Court wrote in *Griggs v. Duke Power Company*,[23] invoking Aesop to construe a statue which imposes only the duty of nondiscrimination in employment (a lesser duty than the Section 503 duty of affirmative action):

"Congress has now provided that tests and criteria for employment or promotion may not provide equality of opportunity merely in the sense of the fabled offer of milk to the stork and the fox. On the contrary, Congress has now required that the posture and condition of the job seeker be taken into account. It has—to resort again to the fable—provided that the vessel in which the milk is proferred be one all seekers can use. The Act proscribes not only overt discrimination but also practices that are fair in form, but discriminating in operation."[24]

R. W. Conley estimated (a conservative estimate probably, made before the affirmative action requirement was adopted) that at least 400,000 of the 690,000 retarded adults, currently idle or institutionalized, could be employed.[25] Section 503—if it is implemented and made real, in fact—provides a necessary and perhaps even the sufficient condition for deinstitutionalization and realizing for each handicapped person a normalized, autonomous life in the community.

The adoption of Section 503, as every Congressional speech preceding it shows, was influenced by *King-Smith v. Aaron*,[26] a decision of the United States Court of Appeals for the Third Circuit, holding that a school district could not deny employment to a blind teacher, by a host of unreported cases,[26a] and by the finding of the courts in the right to education, right to treatment, and minimum wage cases. Litigation and the court findings and orders, and the consciousness created by them, and the public sentiment and the energy of organizations of the handicapped mobilized by them had some place in the complex and open-textured forces focused by Washington lobbyists for these organizations, by members around the country, and by friendly Congressmen to yield Section 503. It would take a political science of much greater sophistication than we have to calculate exacly how significant a place; it is enough to understand that the words and actions of the courts had a place in the kit bag of the Congressional lobbyists.

Similar interrelationships (and similar product in rules change) may be observed between the right to education cases and the Acts requiring zero-reject education and due process adopted by more than 24 state legislatures, the progress of U.S. Senate Bill No. 6, requiring the same and providing federal funding of 75 percent of the excess cost of special education, and the adoption by Congress in August 1974 of Amendements to the Education of the Handicapped Act which required that the states give priority to zero-reject education in the expenditure of federal funds and establish due process hearings, and which singificantly increased authorization of federal funding for education for the handicapped.[27]

Thus far we have noted only the lateral use of the courts to affect other rule-formulating instrumentalities. But the courts by focusing attention have a vertical effect as well on the implementation of the very rights they declare. Shortly after the Pennsylvania findings and orders, the majority leader of one house of the legislature said: "I wish we'd done that." Such sentiments, loosened by the court and nursed by the Association for Retarded Citizens and a new public consciousness, yielded, at Governor Milton Shapp's request, a $25 million increase in the state contribution to special education to implement the newly declared rights.

And it was the action of the Congress in adopting the August 1974 Amendments to the Education of the Handicapped Act that finally made clear to the Department of Health, Education, and Welfare that the Bureau for Education of the Handicapped has the power and the duty to write (and enforce, one hopes they will realize) regulations. The process of consultation with organizations of the handicapped and professionals and the schools has begun. The domino theory, if you will, of implementation. The question remains whether the regulations will have operational definitions and cutting edges to assist in securing the declared rights in fact.

To Announce One's Dignity

The fourth use to which litigation and the courts may be put is to assert oneself, to declare one's own notion of who one is and what one is due, and to change the notions others have (and sometimes one's own notions) of who one is. Participating in a struggle, and recognizing and having it recognized that it is right and good to assert oneself, confirms one's identity and one's confidence in oneself. That in itself is a value, and it is a value, legions of reports indicate, realized by most people in most struggles, and especially in struggles for what is seen as justice, as redress of just grievances. If the use of the courts, or of the due process hearings, or of state and local task forces, like the use of other modes of petition, had only that effect and only on the immediate participants, that use would be significant. But the effect extends well beyond the immediate participants.

Consider blacks and white. After the decision in *Brown v. Board of Education,* the civil rights movement took on still a new life. The recognition and respect for blacks as persons, asserted by those many who litigated *Brown* and those many more who for 50 years prepared, inter alia, to litigate *Brown,* acknowledged by the court, and broadcast by its opinion and the attention thus focused, brought many blacks (who had been coerced by the many times they were told they were inferior to believe they were inferior) to a new respect for themselves and to freedom. And many whites, laboring under the similar debilitating belief that they were superior, came not only to a new respect for blacks, but to a new, less precarious, respect for themselves.

The retarded and the handicapped, their parents, their siblings, their friends, and professionals to whom the retarded are clients have struggled similarly. Subject to the same judgment that we are inferior, many of us came to believe it. Struggling in the name of justice, asserting ourselves, our sense of ourselves changed. Assertions legitimated by the courts, they are broadcast to others who did not participate directly. And their notions change. And thus freed, the likelihood that one will participate in reducing to reality the declaration of one's rights—and the rights of others—increases. A necessary condition of participation in the political arena is some threshold of self-respect, of felt competency, of deservingness to be politically effective.[28]

Kay Gorham speaks of "climbing out of the personal struggle and into the still bigger battles," of "Mrs. Naders popping up all over, where formlery there were timid souls."[29] Dorothy Dean's *Closer Look,*[30] published by the National Information Center for the Handicapped, speaks in terms of rights and coalitions: "It's okay to be different," says one headline. Advertisements for Association for Retarded Citizens, United Cerebral Palsy and Easter Seals no longer speak to sympathy but to rights; themes of charity and grace have given way to themes of justice. The most significant number of the out-of-school children found in Pennsylvania came in not because they were traced in school records but in response to publicly broadcast invitations to "come and claim the rights of your child." The courts and litigation can be and have been so used.

The Comeuppance

But for all this, rights have not become real. There have been few efforts to measure what has happened in the lives of handicapped citizens and what has not[31]—and that is one of our problems. We are left, therefore, with our impressions; and to this observer, the impressions are inescapable.

The institutions stand and have not altered for many, probably for most. Zoning battles are not posed, let alone won; community residences are still at Stage I on the drawing boards; and even if they were built or found, we have not the systems to assure they do not become New York's nursing homes.[32] In some places children are in school, but it is no more appropriate schooling than it has ever been. Hearings are mooted; educational strategies have been tested and found productive, but they have not been widely shared and certainly not distributed to those who must teach. Section 503 exists, but virtually no one knows of it—even those whose profession is developing jobs for the handicapped. For very few handicapped persons, if any indeed, has it yet yielded a job. Even the first steps have not been taken; no one has analyzed the skills required by the contractors' job tasks as they are presently defined, let alone formulated a job conversion table so that in each area of the country there may be a choice of jobs available to fit the skills of each handicapped person.

Symbolic victories—change in the rules—we have had. The problem is that symbolic victories may satisfy and divert us from real victories. We know the courts can be used, as can so much else, to make rules real. But despite the celebration of the last few years, little (except perhaps the change most directly a product of symbolic victories, the increasing sense of self-respect) has happend on the street. Widespread declarations of rights have provided a moment for innovation for the rights to take hold. When the task is—as it is here—to alter deep-seated patterns of behavior which have long since taken on a life of their own in large and complex bureaucracies largely out of control even of those who people them, moments of leverage are rare and hardly expendable. What can be done to seize the moment and to secure the translation of rights into reality?

Before turning to a modest proposal to that end, consider the uses of lawyers. The analysis will be familiar, for the uses of lawyers track the uses of the courts.

The Uses of Lawyers

Questions of using lawyers most effectively resolve to three: (1) What functions shall they be directed to discharge? (2) how shall we organize ourselves in our relationships with lawyers to direct their work? and (3) how can we pay (or change) the costs of using them?

In a paper of productive insight, entitled *Why the "Haves" Come Out Ahead: Speculations on the Settings and Limits of Legal Change,*[33] Marc Galanter distinguishes two classes of litigants: "one-shotters" and "repeat-players." One-shotters resort to the courts only occasionally. They include both parties in custody disputes, divorces, ordinary neighborhood civil suits, commitment proceedings, and ordinary inheritance disputes. They are usually the plaintiffs in suits by welfare recipients against agencies, auto dealers against manufacturers, residents against zoning boards, accident victims against insurance companies, tenants against landlords, and consumers against creditors. The defendants in those suits are usually repeat-players. Repeat-players also include the plaintiffs in suits by prosecutors against amateur accuseds, finance companies against debtors, comdemnor (highways, e.g.) against property owners, landlords against tenants, and I.R.S. against taxpayers. And in cases between unions and companies, movie distributors and censorship agencies, purchasers and suppliers, regulatory agencies and firms in regulated industries, both parties are usually repeat-players. Repeat-players, as the examples suggest, engage in large numbers of similar suits over time.

Whether one is a one-shotter or a repeat-player affects the immediate outcome of any given lawsuit. And even more, whether one is a repeat-player or a one-shotter determines whether one can use litigation to effect long-term real gain.

As to the first, Galanter suggests the advantages that repeat-players bring any piece of litigation: having done it before, repeat-players have advance intelligence; they are able to structure the next suit and to build a record in anticipation of it. It is the repeat-player, for example, who writes the form contract. Repeat-players develop expertise, employ specialists, enjoy economies of scale and low start-up costs for any particular case. They have opportunities to develop helpful, informal relationships with those who people the courts. The repeat-player must establish and maintain credibility as a combatant and has an obvious interest in maintaining hi(r) "bargaining reputations" to establish commitment to hi(r) bargaining position. (S)he can say, "I must have xyz or I can't settle" and be believed.

With no bargaining position to be maintained, the one-shotter has more difficulty in convincingly committing hi(r)self to a particular demand and hence has less bargaining strength. Repeat-players can play the odds. The more important the matter at stake in a particular case is for the one-shotter, the more likely (s)he is to choose a strategy which seeks to minimize hi(r) maximum loss. The stakes in any particular case are smaller for the repeat-player; they can adopt strategies calculated to maximize their gains over a long series of cases and thus can take the risk of a big loss in any particular case. Repeat-players can play for favorable changes in the rules as well as immediate tangible gains. Since repeat-players are in the game to stay, it pays them to spend resources to get favorable rules. A repeat-player can afford the risk of losing in any given rule-change case because (s)he'll be back and hi(r) accumulated expertise will enable hi(r) to present the rules case persuasively.[34]

The position of the one-shotter, if it is social change (s)he is after, is more stark. Galanter writes:

" Our analysis suggests that change at the level of rules is not likely in itself to (bring) redistributive outcomes. Rule change in itself is likely to have little effect because the system is so constructed that changes in the rules can be filtered out unless accompanied by changes at other levels.

"In a setting of overloaded institutional facilities, inadequate, costly legal services, and unorganized parties, beneficiaries may lack the resources to secure implementation; a repeat-player opponent may restructure the transaction to escape the thrust of the new rule. . . .

"The system has a capacity to change a great deal at the level of rules without corresponding changes in everyday patterns of practice or distribution of tangible advantages.

"With their relative insulation from retaliation by antagonistic interests, courts may more easily propound new rules which depart from prevailing power relations. But such rules require even greater inputs of other resources to secure effective implementation. And courts have less capacity than other rule-makers to create institutional facilities and reallocate resources to secure the implementation of the new rules. Litigation then is unlikely to shape decisively the distribution of power in society. It may serve to secure or solidify symbolic commitments. It is vital tactically in securing temporary advantage or protection, providing leverage for organization and articulation of interests and conferring (or withholding) the mantle of legitimacy . . ."[35]

Despite the explosion of litigation, despite the attention at national conventions of handicapped organizations to the law and the courts, despite the host of professional meetings on the subject, despite the creation of a National Center for Law and the Handicapped and the American Bar Association's Special Commission on the Mentally Disabled, our use of the courts and lawyers and the law remains episodic. We are, by-and-large, one-shotters. If we are to make maximum use of the law, we must reconstitute ourselves as repeat-players:

"Coherent groups . . . have the ability to act in a coordinate fashion, play long-run strategies, benefit from high-grade legal services and so on. An organized group is not only better able to secure favorable rule change (in courts and elsewhere) but it is better able to see that good rules are implemented. It can expend resources on surveillance, monitoring, threats and litigation that would be uneconomic for a one-shotter."[36]

In 1934, a potential repeat-player went to the Washington law firm of Covington & Burling with a one-shot problem. With the advice of that firm, they transformed themselves into a repeat-player and to this day they have maintained the full advantage of that status. The Air Transport Association presented a "three-bit problem"—the loss of certain government mail contracts to other airlines in a freewheeling competitive situation. Instead of addressing the problem one-shot, the Association and their lawyers worked four years on a host of fronts to secure a Congressional bill creating the Civil Aeronautics Board and forbidding anyone to engage in air transportation except with a CAB certification of "public convenience and necessity." The members of the Air Transport Association, alone, were certified in 1938 and competitors have since found it difficult to enter this market.[37]

The history of Welfare Rights Organizations over the last decade is the story of the efforts of welfare recipients to become repeat-players and to reap the advantages thereof. Where they have in fact become repeat-players, change has been marked. In Philadelphia, for example, Welfare Rights Organizations negotiated a recognition agreement with the State Department of Public Welfare granting them bargaining rights with the county director, access (and a desk) in each of the 12 Philadelphia District Offices, and the right to represent applicants and recipients in informal relations and in appeal hearings. No one made a claim without an advocate member of the Welfare Rights Organization being present and available to advise and assist and appeal, if necessary. In a year and a half the rate of rejection of new applications for public assistance was brought down from nearly 50 percent to 25 percent. The record of change from welfare lawyering is mixed (and subject still to debate), but, to the extent that lawyers worked for organizations of recipients and the organizations functioned as repeat-players, significant change was secured.[38]

The classic case of the organization for social change becoming a repeat-player is the National Association for the Advancement of Colored People which, from its beginnings in 1909, included among its strategies the use of the courts and lawyers.[39]

The trick, then, is not the one-shot use of lawyers but their systematic use. Many state Associations for Retarded Citizens have a lawyer full-time on their staff. Valuable as that is, one lawyer can attend to little more than one arena (in California, lobbying; in Pennsylvania, the due process hearings) and more likely only to a part of that one arena. One lawyer cannot ring all the legal bells or even plot the legal score; certainly, (s)he cannot respond to the range of possibilities and directions presented by the members of the state organization. Volunteer lawyers, no matter what their skill otherwise or their good will, cannot, without more, build the expertise or the informal relationships or integrate strategies across cases or follow the cases with monitoring, cajoling, threats, or still another case. One-shot lawyers, who are paid, suffer all of the disadvantages of the one-shotter and the cost is prohibitive. One-shots, who are not paid, cost less but remain one-shots—unless, of course, they are among the many legal services and public-interest lawyers who have carried most of the freight in recent litigation. But even at that, these lawyers remain less well integrated with the handicapped organizations than systematic use of them would require.

Thus, if the best use of the courts to secure social change is their use to mobilize political forces to establish the rights of the handicapped in fact, the curious but clear corollary is that we must mobilize to best use lawyers.

A Proposal

City by city, region by region, state by state, Associations for Retarded Citizens join in coalition with other organizations of handicapped persons to create in each city or county and in each state Centers on Law and the Handicapped. With three to eight lawyers at their direction, the coalition of organizations would become repeat-players and could pursue the full use of the law; integrated short and long-term strategies, in the courts and in other arenas, follow through.

Cost inhibits the use of lawyers and of courts. But coalition can make it go. Full-time staff lawyers are available for work which concerns social change at considerably less dollar cost than lawyers in the ordinary open market even at a discounted fee.[40] An optimum three-lawyer office can be staffed for about $80,000.[41] The cost then to an eight-organization coalition will be $10,000 per organization per year; to a four-organization coalition, $20,000 annually.

But the benefits of coalition and of staff lawyers are not merely the dollar economies; coalition offers economies of function and of impact in the uses of the law as well. The members of the several organizations of the handicapped share, after all, a common social situation and similar experience. Their needs and wishes will, in significant degree, be similar. The fabric of the law intersects with the experience of each in similar ways. Cases will be stronger; opportunities and problems susceptible of legal address are more effectively and efficiently addressed together. Zoning and building regulations, which inhibit or prevent the development of residential facilities in the community, and supplemental security income regulations, which delay or exclude handicapped persons, will affect persons with different handicaps in the same way. What will resolve the problems of some persons will resolve them for almost all. What will open access to public transportation and to community services (from education to recreation), what will assure the quality of residential services to some, will for others too. Redesign of job tasks and job settings to open employment to handicapped persons will be secured most surely and most efficiently if it is sought with all the handicapped in mind. Often the gaps and the blocks to realizing the rights of the range of handicapped persons will have their origins in the same mistakes in writing or interpreting state and federal statutes and regulations, in judging competence, in designing programs, or in just plain oversight. Often the remedies required, as well as the targets, will be the same.

The benefits of coalition extend, however, beyond the direct uses of the courts and other legal forums. The indirect uses of the courts to marshal forces in other political arenas are advanced by coalition. Coalition can seize the opportunity for authoritative pronouncements of the courts to stir the confidence of more people to seek more deeply, more widely, and more skillfully the realization of rights in fact. It can do this by using the burgeoning handbook of strategy to place at the fingertips of handicapped persons and their parents and advocates clear and precise understanding of the rules and of how to use them to thread particular problems,[42] by training lay advocates for hearings and for work on local task forces, by mobilizing strength in the legislature and elsewhere. Vestigial rivalries among handicapped groups may be muted in a common pursuit of rights, and the common strength of the handicapped may be increased.[43]

Services received from lawyers should be of a different and better quality when lawyers work full time at the direction of a coalition of organizations. Committed full time to the pursuit of the rights of the handicapped, and informed, guided and directed by the citizens most knowing of the problems, of the relationship between the problems, and of the sought-after resolutions, lawyers may probe more deeply, more widely, and focus more on target. The sometimes intricate and obscure set of federal, state and local statutes and regulations, which so largely determine for good or ill the quality of life of handicapped persons, may be searched and parsed systematically to discover what claims, yet unfound, lie there. The possibilities of invention in the common law of tort, contract, and property may be explored and exploited. And follow-through (in all of its dimensions) may be addressed.

Given a local Center on Law and the Handicapped, volunteer lawyers can now be used effectively. The core lawyers can share expertise in handicapped law, provide the strategic connections between cases and coordinate follow-through.[44] One-shot lawyers, paid and not paid, may now be used more effectively; indeed, given a local Center on Law and the Handicapped, more refined judgments can be made on marshaling non-Center lawyers especially expert in particular matters for particular cases or parts of cases. And as the award of attorneys fees to prevailing (or even failing) plaintiffs in cases for the handicapped becomes more common,[45] and as prepaid insurance-type legal service plans for union members and other groups are established more widely,[46] the role of local Centers in sharing expertise and coordinating strategies will become the more important, the use of lawyers the more widespread, and all the more effective in securing change.[47]

Local, regional and statewide Centers on Law and the Handicapped might begin in a number of ways. They might spring full-blown in coalition from the several organizations of the handicapped. One or a few such organizations might start the Centers, recruit additional organizations and resources to the coalition later; thence expanding the scale and the scope of the Centers. In some communities, where bar associations have significant financial resources, Centers might be launched with contributions from the bar. In those communities where state and federally funded Regional Centers, or Mental Retardation Centers, or Developmental Disability Centers, or University Affiliated Facilities exist (and they are existent in various forms and under various names in virtually every local community in the country), they might contribute start-up resources. Indeed, where state and federally sponsored Mental Retardation Centers, however named, evince an interest in themselves asserting the rights of their handicapped clients against others, they might become long-term members of the coalition and partners in the Centers on Law and the Handicapped. Over the long term, the increasing resources of the organizations who are members of the coalition, an improving public consciousness, and increasing attorney's fees awards from the courts, should render the local Centers stable institutions, a taken-for-granted part of the expanding effort of handicapped citizens to effectively claim their rights.

Roles for Professionals in the Bureaucracy

The uses of litigation and the courts present new role opportunities for mental retardation (and other handicap) professionals who practice in the bureaucracies: as plaintiffs and as defendants.

The Plaintiff's Role

Wyatt v. Stickney, the Alabama right to treatment case (it will surprise many to know), was begun not by the residents or relatives or the Association for Retarded Citizens, but by employees of the institution. In the face of a cut in the Alabama cigarette tax, the state fired 93 professional, sub-professional and intern employees of a state hospital. The terminated employees took to federal court to contest the firings, asserting, inter alia, that residents of the institution would not receive adequate treatment. As the case developed, its focus changed and the claim became: even with the employees reinstated, Alabama's institutions do not provide adequate treatment. The rest is history, albeit current history.[48]

Professionals in the bureaucracy have the right to assert the rights of their clients, even to assert the rights of their clients against the bureaucracy in which they work. Indeed, professionals in the bureaucracy may well have a duty—a legal as well as professional duty—to assert the rights of their clients.

The Right To Assert the Rights of Clients

On January 13, 1973, at 6:30 in the morning, Benny Parrish, a public assistance case worker in Oakland, California, was instructed to join "Operation Bedcheck," a search of the houses of public assistance recipients—"especially the beds, closets, bathrooms, and other places of concealment," to determine if there was a man in the house and, hence, whether assistance could be terminated. He refused, asserting that such searches were illegal. He was fired for insubordination. The County Civil Service Commission upheld his firing. But the California Supreme Court, in a unamimous opinion, held that Benny Parrish was protected in his right to assert the rights of his clients and ordered him reinstated.[49]

On the evening of July 27, 1976, Ocania Chalk, a public assistance case worker in York County, Pennsylvania, attended a meeting of public assistance recipients, a group called the Public Assistance Committee. There, he criticized the personnel and policies of the York County Assistance Office. He urged recipients to "get on case workers' backs and demand their rights;" he stated that some case workers failed to accord recipients dignity and to inform them of their rights of appeal; and, quoting Frederick Douglass, he exhorted recipients to "agitate, agitate, agitate." He was suspended from his job without pay for "having caused embarassement and unfavorable publicity to the department." The State Civil Service Commission upheld his suspension. But the Pennsylvania Supreme Court, generally more conservative than California's, reversed, holding Ocania Chalk's remarks protected by the First Amendment. "As a member of that governmental institution (York County Assistance Office)," The Court found, "he had a unique, and valuable, perspective, from which to view it." The benefit of that perspective could not be denied to his clients or to the public.[50]

From 1966 through 1969, Father Joseph Donahue,[51] Chaplain of Manteno State Hospital in Illinois ("a gigantic institution operating on a skimpy budget," as the court put it), engaged in a campaign of public criticism of the institution. He wrote in a union newspaper column; he addressed the State Federation of Labor and made other public speeches; he wrote letters to the governor and to the editor of the local newspaper; and he published a paid advertisment in that paper. He complained, inter alia, of insufficient employees, unqualified employees, inadequate care, and in the paid advertisement criticized the Director of the Mental Health Department and the Superintendent of the Hospital. In 1969, he was fired. He sued in federal court for reinstatement. He won and was awarded back pay, punitive damages and attorney's fees.

There is a very significant space in the bureaucracy within which the professional is protected in asserting the rights of hi(r) clients, even against the bureaucracy itself. Thus, e.g., a Regional Mental Retardation Center psychologist whose child-client has been denied schooling may assert hi(r) right to schooling against the school district, perhaps into court. And a teacher may assert in a due process hearing hi(r) professional views of the appropriate educational program for hi(r) client even if the district's official view is to to the contrary. Indeed, the bureaucratized professional may have a duty to do so.

The Duty To Assert the Rights of Clients

Donaldson v. O'Connor,[52] the Florida right to treatment case holding two physicians personally liable in damages for failure to treat a state hospital resident, suggest, though it does not reach, the question of whether a bureaucratized professional does not have a duty to assert the rights of hi(r) clients. The defense of the physicians to the claim of liability was that they did "the best they could given the stark limitations on the resources available to them." If the court had found the defense true, the next issue would have been whether the doctors would have had to show a good faith effort to secure sufficient resources in order to escape liability.

A Pennsylvania case suggests the answer is yes. The superintendent of a state hospital was fired for dereliction of duty. It was alleged, inter alia, that residents were maintained in unsanitary cages. His defense was lack of funds, understaffing and overcrowding. On a finding that the superintendent had made inadequate protest of inadquate resources, the State Civil Service Commission upheld his firing.[53]

The duty of the bureaucratized professional may arise both from hi(r) status as a professional and from hi(r) status as a statutory fiduciary. As a professional, by definition, (s)he is possessed of some special knowledge and, by definition and by the Codes of Professional Responsibility of virtually all professions, (s)he is bound to use that knowledge to serve hi(r) client.[54] As to fiduciary duties derived from statutes, consider two common statutory provisions; one, Section 1501 of California's Community Care Facilities Licensing Act:

"It is the intent of the state to develop policies and programs designed to . . . (2) assure that all people who require them are provided with the appropriate range of social rehabilitative, habilitative and treatment services including residential and non-residential program tailored to their needs;"[55] Another, Section 4201 of Pennsylvania's Mental Health-Mental Retardation Act:

"The Department shall have the power, and its duty shall be: (1) to assure within the State the availability and equitable provision of adequate mental health and mental retardation services for all persons who need them."

Such provisions must impose a duty upon the bureaucratized professional; a duty owed, if not to client, then at least to the state. If resources are inadequate to deliver on these statutory injunctions, the least that can be expected of the bureaucratized professional is that (s)he holler about it, inside and outside the bureaucracy.

The Defendant's Role

At least two very different styles of response have arisen in bureaucrats across the country to litigation against them. Some take lawsuit litigation personally, becoming very defensive. Others recognize the uses of litigation and, in effect, welcome it. They see that litigation is targeted at objectives which they, as professionals, share and that it will provide them with additional leverage toward their objectives. (The right to education cases, for example, spring directly from the Council for Exceptional Children's Policy Statement of 1971; and the right to treatment cases spring from the Accreditation Standards of the Joint Commission on Accreditation of Hospitals.)

The bureaucrat's response is important to the pace at which a suit will proceed. And hi(r) response and attitude is crucially important to the pace and the thoroughness of implementation. The first (defensive) response may have its roots in mistaken notions about the nature of litigation or in styles of personal involvement and notions of change and truth which may themselves be profession-rooted or, at least, occupation-rooted.

If the source of the defensive response of bureaucratized professional is mistaken notions about litigation, these professionals are hardly alone in the mistaking. Virtually every civil procedure casebook presently in use in the law schools of this country contains a ritual recital "on litigation as the last resort in the resolution of disputes, short of violence." Such a recital, and defensive feelings, may have made sense in the Middle Ages when a trial was by fire: whoever survived the hot coals in better shape was right and won. It makes no sense now.[56] Litigation, as the analysis offered here indicates, is fundamentally like every other method of resolving disputes or of petitioning the government for redress of grievances; each of the methods has in some degree its own peculiar costs and benefits.

As a descriptive matter, the analysis indicates, litigation is hardly the last of anything; most often, for repeat-players anyway, it is merely a beginning. And if "litigation is the last resort" means that one will or should try every other means of resolving a dispute before turning to litigation, that obviously depends upon the circumstances: upon the relative accessibility (and the costs of access) of other methods; upon which method is most susceptible to the sorts (and the size) of resources one can put behind hi(r) claim; and upon a host of other contingencies. For those to whom, because of prejudice, "the political processes ordinarily to be relied on" are effectively closed—in short, for those who are different—litigation may be the first resort.[57]

Suits against governments for injunctions are not personal unless one chooses to make them so. They are addressed to changing things as they are and have no function in allocating blame. If blame is involved at all, it is systemic, not personal—except in the cases where systemic failure is indeed personal or is personally caused or personally abetted. The same is not true, of course, for personal actions for damages, though the modern view of damage actions regards even them as mechanisms for the allocation of costs, without tones of blame or fault.[58]

Contrasting styles of response among bureaucratized professionals, in some instances, may be caused (or accentuated) by differing notions of how change comes. The bureaucrat, classically, believes that proper change comes (if it is to come at all) hierarchically. Some professionals may join the bureaurcracy because they so believe; others, whose notions were different or inchoate when they were selected, may have since been socialized by bureaurcracy to that belief; truth is found and proper change comes dialectically in the contest of thesis and counterthesis. It will be of little comfort to say to the bureaucrat schooled in hierarchy: have faith, join the contest, bring to bear your best information and your best opinion—justice will out. Lawyers, after all, have been schooled in the dialectic, to joy in expression and assertion, to take the outcome without personal involvement (not necessarily to accept the outcome, for in another forum another result may be obtained), and to leave the courtroom with their arms thrown around the shoulders of opposing counsel. But that may be all that can be said to professionalized bureaucrats to remove the sting.

There are, of course, hard cases in which the bureaucratized professional will have a position opposed to the particular position of particular handicapped plaintiffs (and also there are easy cases in which the professional in the bureaucracy must, for one reason or another, taken an opposed position), in which case (s)he must join the contest and bring to bear hi(r) best information and hi(r) best opinion. But in those cases, once the verdict is in, implementation (or not) can proceed without cavil.

Functions for Professionals in Research

Litigation and the orders of the courts have been built upon the findings of mental retardation (and other handicap) professionals in research. The same questions raised about the uses of law and of the courts must be raised about professional research. Can research evoke only hortatory changes in the rules, undergird only symbolic victories? Can research effectively address implementation? As before, any answer that relies only on the description of what has happened must be grim. To date, research has not produced or packaged findings which are sufficiently systematic, precise, or coherent to support change in fact.

But the productivity of research like the uses of the law) need not be confined to symbol and exhortation. Research can contribute to the implementation of the rights of the handicapped just as the courts can, and even more directly. Indeed, the rights of handicapped persons cannot be made real in fact unless research is focused upon implementation.

First, the grim descriptive facts of the present and a suggestion for their remediation. Second, a few suggestions for priority on the agenda of research for implementation and impact. Third, a comment on the relationship between research, the law and change in fact.

Packaging

With perfect fidelity to research findings, expert professionals can testify that all handicapped children can learn. But in the 36 states now under legislative or court injunction to provide an appropriate program to all handicapped children, many teachers do not know how to teach them. Experts know that for every sort and combination of handicapping condition, somewhere in this wide land, educational strategies and techniques have been invented, tested and found productive. For all our investment in curriculum development, learning materials, teacher training and continued training, many teachers do not know what to do or where or how to find out what to do. And for good reason. What is known is neither collated nor indexed nor is there a distribution system to equip teachers and children to realize the opportunity which is theirs.

No matter cries out more urgently for address than the design, development and production of schemes for ordering and distributing present knowledge. Research in packaging research, and its use immediately!

The Laboratory Around Us

Some 36 states are now committed to experiment in the right to appropriate education; some 12 states are committed, by legislative or court injunction, to experiment in the right to treatment. The largest single laboratory in social change (excepting only racial desegregation in the aftermath of *Brown*) and the largest single laboratory ever to retest and to confirm or to alter previous findings on the development of retarded persons, on learning, theory and techniques, on theories and techniques of habilitation and rehabilitation, and so on, is thus available at our fingertips. Astonishingly, the laboratory is empty.

The hunger for fuller and more exact knowledge of the processes and techniques of change is acute. How is the productivity of committees on human rights or of masters or of local and state task forces (in terms of rights in fact) affected by differing composition of the task forces? By differing formal and actual definition of their powers and duties? By differing skills, attitudes and experience of members? By ad hoc training, or its absence, in the uses of task forces? By differing training? By differing schedules of meeting and differing mechanisms of structuring agendas? By differential location of the task force in the organizational hierarchy? By differing relations of each of its members to the constituency of each member? By whether task force meetings are private or public? By differing task force access to records and personnel of the school district or the institution? By diffential sanctions (informal and formal) available to the task forces?

How is the productivity of due process hearings (in terms of rights in fact) affected by where they are located in the hierarchy (at the top with the Secretary of Education, for example, or in tiers across the system); by the professional identity of the hearing officers; by the screening mechanisms and the criteria used in their selection; by the formal aspects of the hearing itself; by the representation of hearing complainants variously by lawyers, by Association for Retarded Citizens advocates and by others; by the training and preparation of the advocates; by differing role perceptions of teachers and administrators, defendants in the hearings; by the nature, skill and type of independent evaluations of program available to complaining parents or children and of the personnel who conduct the evaluations; by the bureaucratic, professional, consumer and policitical cultures in which the hearing mechanisms operate? What effect do differential hearing processes have on ordinary, day-to-day behaviors and decisions (not themselves the subject of hearings) in the classroom and in the bureaucracy? What effect do varying techniques of individual prescription have on educational outcomes; what are the necessary conditions (in terms of training, socialization, skills and attitudes) of productivity (in terms of educational outcomes) of prescriptive techniques; is the participation of the student, the parent, the resident in the design of the prescription among those necessary conditions; in what ways is that condition most effectively fulfilled? What effect do differential handbooks used by handicapped persons and their advocates in differing ways, with differing training of the users, have in changing the behavior and decisions of the schools and the other institutions?

If what we suppose about the effects of litigation and declarations of rights on self-perceptions, self-confidence and felt-dignity, and, thus, on lossing the energy of people for political action is true, what are the necessary and sufficient conditions of such effects and how do they vary among people in differing social situations? If it is true that authoritative injunctions by courts and legislatures to educate every handicapped person liberates great creative energy in the teacher (after the initial fright has passed or been mastered), how long does this creative energy last? Is there a critical period after which, if the teacher does not get assistance and reinforcement, hi(r) creative energy dissipates? What are the necessary and sufficient conditions of supplying that reinforcement? And, indeed, are there, as a general matter, critical periods after any declaration of rights after which, if the necessary and sufficient conditions of implementation are not supplied, the opportunity passes?

What are the differential consequences of differing formulations of declarations of rights by courts and by legislatures? What differences in the structure of remedies result in what differences in the realization of rights? What styles of Associations for Retarded Citizens, of lawyers, of other professionals most effectively conduce to change? What are the necessary conditions of those styles and the necessary conditions of change in fact?

Even the casual observer could multiply the questions with profit. Their answers will have an immediate place in the redesign of strategies for change, in altering the mechanisms we use to seek change. Varying mechanisms and varying strategies are in use now more intensively in more places than ever before. Participant observation, multivariate analysis, the host of more or less precise and thorough techniques of modern research—and just plain taking a good, hard, careful look at what is happening and what is not—can be used to gather and sort and analyze the very rich data in the great wealth of events occurring across the country. The findings will be rich. They will refine our theories of social change and they can increase our wisdom in seeking it.[59]

Similar questions can be formed for research in developmental and learning theories. In very many places, people are trying out what we think we know about development and learning. And since in many places, others don't know what we think we know, they may be trying things we don't know. Whichever way, the very number of the new tries provides an unparalleled opportunity to validate and refine and perhaps to renew our understanding.

Section 503

If Section 503 of the Rehabilitation Act of 1973 can be made an engine of deinstitutionalization, securing to handicapped persons a life of liberty, relative autonomy and choice, in an integrated setting, it will only be made so if the necessary research is forthcoming. To translate the delcared statutory duty of government contractors to hire and advance handicapped persons in employment into regulations that will bind and litigation that will make a difference, certain things must be done.

On the legal side, it must be recognized that affirmative action requires the government contractor not only not to discriminate, and affirmatively to reach out to recruit and hire, but also to redefine job tasks and job settings to fit the handicapped to the extent necessary to provide employment to all handicapped persons.[60] To give that duty operational—and enforceable—meaning, research must tell us what the "extent necessary" is.

That requires the development of a typology (or several alternative typologies) of competence and their distribution and incidence among all the handicapped. The typology of competences may be constructed from a systematic collation of occupations in which handicapped persons (of all the various capacities) have engaged. Two additional kinds of typologies are required. First, a typology (or several alternative typologies) of required job competences for job tasks in job settings as they are defined and as they exist now among government contractors. The typology of competence required may be constructed from an analysis of job tasks in job settings presently existing among, say the 500 largest and most constant government contractors. Then, using a conversion formula derived from experience in redesigning job tasks and job settings to fit the handicapped, a third typology (or set of typologies) may be constructed to display, with particularity, the converted (and unconverted) job tasks which must exist in altered (and unaltered) settings among government contractors in each area of the country if each handicapped person is to have, say, three jobs which fit hi(r) competence available for choice.

Minimum Quantitative Standards for Community Services

Recall the California and Pennsylvania statutory injunctions recited above. Pennsylvania, for illustration, provided: "The Department('s) power and its duty shall be to assure the availability of adequate mental retardation services for all persons who need them." Similarly phrased provisions dot the education, welfare, housing and recreation statutes of virtually all of the states.

The problem is these are declarations—the right to "adequate mental retardation services," for example—without operational definition. When the crunch comes and the inquiry is whether such rights are real, it is often discovered that resources have not been made available and the declaration is violated—waiting lists abound, needs are snubbed, claims are mooted, some lives are laid waste (often imposing a greater cost on the government later).[61]

Two strategies may serve to address the problem of operational definition. One, the strategy of the right to education cases is to consign the definition of a phrase like "a program of education and training appropriate to the capacities of each child" to hearings and the administrative process, and to structure that process so that the only question for decision is the appropriateness, educationally, of the student's program. Considerations of resources are, in the education cases, excluded (in the formal, legal sense at least) from the hearings and from the judgment about appropriateness. The cases are explicit that cost and the purported scarcity of resources are no defense to the failure to provide each child hi(r) due. The integrity of judgments about educational appropriateness is protected (in the formal sense) by the availability of judicial review of the hearing to assure procedural regularity (impartiality of the decision-maker, notice, the opportunity for an independent evaluation of the student and hi(r) educational program, the opportunity to be represented by a person of one's choosing to present evidence, the opportunity to cross-examine, and the requirement that decisions be made solely on the basis of the evidence presented at the hearing) and to assure that the judgment is not so far wrong as to be patently arbitrary and irrational. The strategy of the structured, individualized hearing is proper when, in an area like education, there is much uncertainty about input-output relationships and the best one can seek is a fully informed shot at bringing the best professional opinion to bear on the finding of appropriateness. To be sure, the hearing, and the findings themselves, will be structured by the allocation of the burden of proof, by presumptions like the one imposed by the courts in favor of the most integrated setting, and by rudimentary minimum quantitative standards (like student-teacher ratios) which have long since characterized special education.[62]

The institutional right to treatment cases illustrate the other strategy. The genius of *Wyatt v. Stickney* is its adoption of minimum quantitative standards to give content to the duty of the court found in the Constitution to provide "adequate treatment" to all involuntarily committed resident. For 10 years before *Wyatt,* right to treatment litigation wrestled with the problem of what might constitute adequate treatment. As with education, but even more so, there was great conflict of opinion about what might constitute adequate treatment for any given person. And, in many instances, perhaps most, the courts would be incompetent to resolve the conflict. The conundrum was solved in *Wyatt* (formally at least) by avoiding the question of adequacy of treatment in any given instance, by adopting minimum quantitative standards and requiring individualized treatment plans and leaving the rest to process. The court adopted the Accreditation Standards of the Joint Commission on Accreditation of Hospitals which, in turn, were the product of extensive work by research and practicing professionals.

Guarantees of "adequate services" in the community may be taken a step toward realization in the same way. Research and the formulation of minimum quantitative standards might proceed from analysis of incidence of various handicaps, admixing the best prevailing professional judgment about minimum services necessary to a full and relatively autonomous life in the community, to minimum quantitative standards, varying by community size, of the generic programs required, and minimum staff skills and ratio.

With these standards in hand, litigation may proceed to give operational definition to guarantees, like Pennsylvania's, of services in the community. A similarly phrased provision in the federal Social Security Act provides that "aid to families with dependent children shall be furnished with reasonable promptness to all eligible individuals." Again and again, the Supreme Court has held that this provision means that if one is eligible, then aid must be furnished.[63] The difference is that both "eligibility" and "Aid to Families with Dependent Children" are given operational definition by the Act itself and in federal and state regulations under the Act. Neither "services" nor "persons who need them" are defined in or under the Pennsylvania Act. Minimum quantitative standards, however, would, as in *Wyatt,* keep the courts out of the business of defining who needs what services, but put them in the business of policing palpable, measured standards.

Discussion of minimum quantitative standards raises certain questions about strategy in the use of the courts and about the wisdom, or place, of securing detailed statements of standards in the law. The very genius of *Wyatt* is its danger. It is now painfully clear that the institutional right to treatment cases contain the risk of reifying the institution.[64] A priori one might have thought that a minimum standards order would cause the institutions to tumble; that the cost of maintaining the institutions to standards would have proven prohibitive to the state; that the state would, therefore, choose alternative, less costly settings for treatment. That possibility still inheres. The data is not yet in. And the ultimate outcome is still subject to influence and control by partisans of deinstitutionalization (if we mobilize ourselves effectively). But when the court issues an emergency order directing the employment of 300 additional resident care workers and those workers are hired,[65] that, without more, props up the political case by at least 300 additional citizen-constitutents-of-legislators-and-governors who have a stake in maintaining the institution. The perception of the risk of reifying the institutions suggests that court strategy in the institutional cases might better be focused on the "least restrictive alternative" aspects of the case:[66] seeking to secure operational definition of the duty to provide treatment in the least restrictive setting (perhaps, indeed, minimum quantitative standards for treatment in the community, and a timetable for moving institutional residents to adequate, small facilities in the community). Indeed, it should be noted that the Fifth Circuit Court of Appeals, in its decision affirming *Wyatt v. Stickney*, recognized that the minimum standards had entered the case below by stipulation of all the parties, expressly declined to reach a decision as to whether those standards are constitutionally minimum requirements and, still more important, expressly declined to decide whether a federal court may prescribe standards at all "as distinguished from enjoining the operation of such institutions while constitutional rights are being violated." [67] (Emphasis deleted)

In any case, the contribution of the *Stickney* standards to reifying the institutions can at best only be marginal; the political forces and the inertia which protect the continued existence of the institutions are altered hardly a jot or tittle by adding another few hundred employees. It is those facts of political life that make so pressing the need for minimum quantitative standards for services in the community. Parents in some significant number oppose deinstitutionalization for a host of reasons; a most important one being that there is no assurance that services will be available in the community—nor even, it sometimes appears, a fighting chance that they will be.[68] Employees of institutions—and a politically salient number they are: 14,000 in California in 1975, for example, and 17,000 in Pennsylvania—similarly have no assurances, either that they will have jobs after deinstitutionalization nor, to the some significant number of employees who may have such concerns, that their professional responsibility to their clients will be discharged in the community. The formulation, and authoritative promulgation, of minimum quantitative community standards would be a step toward such assurances. They would provide a focus, a rallying measure; something to holler articulately about and against which to measure progress toward right in the community in fact; something enforcible.

Minimum quantitative community standards, just as minimum quantitative institutional standards, raise another question: apart from reifying the institutions (or the community), there is a danger of reifying the standards themselves. On the one hand, the conscientious researcher and citizen, and the activist, know that quantitative standards formulated today will be no good the day after tomorrow. There will be new research, new modes of service, new lifestyles, new economies, new professions even, a changing incidence of handicapping conditions, and new senses of what is the minimum—on the basis of which quantified minimum standards should also change. On the other hand, we have seen the uses of operating definitions, of cutting edges: to measure whether the handicapped are getting what they are entitled to; more easily to prove and to enforce their entitlements (starkly easier than with words like "adequate"). A battle once won and a measure established in fact, then—until battle needs be joined again—the measure need not be defended (and the defense probably lost) day by day.

Thus, we need minimum quantitative community standards, but we do not want to be stuck with them when they are outdated. Should we then create them? This dilemma is a false dilemma. It is resolved by classic administrative law doctrines. Certain standards—those of a high level of abstraction, like "adequate services . . . for all who need them," which set the purpose, the tone and the direction—should be promulgated by the legislature or by the judiciary. Other standards—the concrete particularized minimum quantitative standards for services in the community, for example, should be promulgated in regulations by the executive or administrative. By hypothesis, regulations are more easily changed than statutes or judge-made law. (In any particular case, and ours may be one, the reverse may be true. It may be easier to change Congressional enactments than to change HEW regulations, for example. In the states, the effort to secure minimum quantitative standards from the executive in regulations may be prejudiced by intrinsic conflicts between the executive function in budget-making and its function in achieving purposes and directions set, abstractly, by the legislature. In any given case, the place we will choose to seek the promulgation of minimum quantitative standards will depend on the vector of the forces which bear on the respective places and upon our access and strength with them respectively.)

On the classic view (and it is a correct view generally), if standards become reified in regulations, and stale and no longer responsive to the legislative purpose and direction, resort may be had to judicial review to void the stale regulations and to start the process of writing new ones. As the Supreme Court said long ago in another context:[69] "The constitutionality of a statute predicated upon the existence of a particular state of facts may be challenged by showing . . . that those fact have ceased to exist."

By the same token, regulations promulgated to effectuate legislative purpose and to discharge legislative direction may have done so once but when the facts have changed may have ceased to do so.

Minimum quantitative community standards raise still one more question: the question of reifying labels. And this question may constitute a true dilemma. After all, there presently do not exist now for the general run of citizens general rights to minimum services necessary to life in the community, general rights to a minimum income, for example, or to a job, or to housing, or to health care.[70] (Though for certain special services—such as education—such rights may exist for the generality of citizens.)[71] But some such services do exist specially for handicapped citizens (and all of this paper is part of the wide effort to render them services of right). Therefore, whenever any handicapped person consumes such services, (s)he marks hi(r)self special and in some sense "submits" to labelling. The dilemma is not resolved by saying that, if such services were delivered by generic service agencies, labelling of the handicapped would not occur since (among other reasons), for many services, there exist no generic agencies (just as there exist no general rights to certain services). The dilemma will, of course, be resolved truly if and when general rights to services are recognized (and here, of course, is where the wider coalition comes in).[72] For now, it may be said that any minimum quantitative standards for community services to handicapped persons will reify the labelling process.

When there is no gain at all from getting services which carry a lable, the dilemma dissolves, This is what the *Dina* case, *Larry P*, and the rest of the misclassification cases are in part about.[73] There the question in part is the assigment of mildly retarded students to special, EMR classes. Since research is persuasive that there is no educational benefit to be gained by mildly retarded students from special classes,[74] it would clearly be irrational to submit to the label such classes bring. (Note that even when we go to full integration of the mildly retarded into regular classes, labelling may still creep back in, for most mainstreaming plans contemplate some special "resource room" or "resource teacher" attention. Labelling will be dismissed significantly, but will linger until every student, handicapped or not, receives special, individualized attention in regular schooling; in other words, until all regular schooling becomes "special.") When there is no gain in return for the service, resolution is easy.

The hard cases arise when there is clear gain from the service and clear detriment from the accompanying label, and when the questions of service gain or label detriment are uncertain and problematic. Consider, for example, Section 503. Should the mildly handicapped adult be blanketed into the group covered by government contractors' duty to employ and to advance in employment? Yes, because probably with the aid of Section 503, the mildly handicapped person can secure more remunerative and constant employment. No, because no matter how well his particular job is integrated into the work setting and no matter what prophylactic devices are invoked to secrete the records, probably word will go out that he is "here on quota," "our house dummy." Put this way, the question begins to look like a question of who shall decide whether the gain of Section 503 service outbalances the cost of the label. Perhaps, therefore, the regulations implementing Section 503 should extend coverage to the mildly handicapped, and simply leave it to each mildly handicapped person to weigh the gain and the cost and to choose. If the dilemma is to be resolved by each mildly handicapped person, what of the moderately handicapped person, the severely and profoundly handicapped person?

As suggested twice, just above and throughout by the attention to coalition, this dilemma may be obviated only by creating integrated space for difference to thrive, by altering the meaning of "difference," and by generalizing the perception of individual differences. A strategy of rights and of services has particular salience to these tasks. The sought-for outcome is that each citizen (handicapped and not handicapped) is recognized and respected as different (not as more different than in fact (s)he is, for that would be sterotyping, nor as less different than (s)he is, for that would be denial.) "Difference" is purged of the invidious because difference is universal and celebrated. And that's what the First Amendment, and the Constitution, are all about.

Surveying the Opinions and Attitudes of Handicapped Persons

For years we have surveyed, in a host of clever ways, the opinions and attitudes of the public, parts of the public, legislators, opinion-makers, parents, siblings, friends, associates, teachers, would-be teachers, employers, would-be employers, just about everyone we could think of, toward the handicapped. We have not, however, sought assiduously to determine the opinions and attitudes of handicapped persons themselves. By and large, we have not consulted them at all. Yet, their opinions are crucial on any number of questions central to the struggle for change. There are, of course, exceptional pieces like Edgerton's conversations with "feebleminded women" about their feelings and opinions after their sterilization.[75]

More extensive and intensive surveying will require most creative uses and perhaps adaptations of methodology. The retarded, for example, are different after all and engage little in hypothetical thinking.[76] The usual structure of survey instruments ("If I could have A, B, C, or etc., I would want Q") may not do. In addition to whatever methods of direct search of opinion and attitude, research may proceed by structuring choice and attitude-expressing situations. Such research will, like any research, be susceptible to the dangers of manipulation and the control effect and to risks of error in interpretation. But we may learn not only a great deal about the preferences of handicapped persons themselves but also much that is urgent for us to learn about how to consult the handicapped.

Identity and Roles of Clients and Lawyers

The preceding analysis suggests three separate observations about clients and lawyers, which after all may not be separate but central to the uses of lawyers. One observation is on clients, another on lawyers, and a third on the intermediate fate of both.

Identity of Clients

Standard legal doctrine about parties in litigation requires that a court may not come to a binding decision unless all "indispensable parties" have had an opportunity to appear before the court and to be heard. Indispensable parties, the Supreme Court said in 1854, are:

"Persons who not only have an interest in the controversy, but an interest such that a final decree (determining the entire controversy and adjusting all the rights involved in it) cannot be made without either affecting that interest, or leaving the controversy in such a condition that its final termination may be wholly inconsistent with equity and good conscience."[77]

Handicapped persons themselves, therefore, would appear to be indispensable parties in any controversy where the rights of handicapped persons are being asserted.

Mr. Justice Douglas, dissenting in part in the recent successful challenge by the Amish to compulsory high school attendance, made a similar point. (To the reader, the invocation of the following words of Douglas may seem to betoken the common sterotypic pattern identifying handicapped persons with children. That, of course, is not the intent; rather the assertion is, what is said of Amish children by Douglas may be said, mutatis mutandis, of handicapped persons, whether children or adults, and universally, of all persons.)

"I agree with the Court that the religious scruples of the Amish are opposed to the education of their children beyond the grade schools, yet I disagree with the Court's conclusion that the matter is within the dispensation of parents alone . . .

"These children are 'persons' within the meaning of the Bill of Rights. We have held so over and over again . . .

"On this important and vital matter of education, I think the children should be entitled to be heard. While parents, absent dissent, normally speak for the entire family, the education of the child is a matter on which the child will often have decided views . . . It is the student's judgment . . . that is essential if we are to give full meaning to what we have said about the Bill of Rights and of the right of (persons) to be masters of their own destiny."[77a]

These themes are expressed in the order of the court in *Horacek v. Exon* (the right to treatment in the community case) appointing on its own motion a guardian to represent retarded persons in the litigation because the interests of retarded may be different from the interests of the parents.[78] The recent cases holding the "voluntary" commitment of handicapped children to institutions by their parents is unconstitutional without a hearing and representation of the children reflect that concern.[79]

As a general matter (apart from the cultural fact that in the courts virtually no one represents hi(r)self, virtually everyone is represented by a lawyer),[80] substituting one representative (the guardian) who may or may not perceive the retarded person's interest as the retarded person himself perceives his interest for a representative (the parent) who may have conflicting interests but who may also be more likely to perceive the retarded person's interest as the retarded persons perceives it is a problematic gain. (Except, of course, from the perspective of the lawyer's conviction that the more interests, or perceived interests, contending, the greater the likelihood of truth and justice.) In either case, we may be no closer to securing the expression of the retarded person.

The point is not limited to expression in litigation, but extends also to expressions to guide and direct other lawyering functions. And still more generally and even more important, it extends to expression to guide the full campaign for rights. A recently founded organization of young, physically handicapped persons, Disabled in Action, may express different sentiments and objectives than an organization with a different mix of handicapped and nonhandicapped membership. In England, Scandinavia, and a few places here, Associations for Retarded Persons are beginning to take shape, which may or may not express more faithfully the desires and opinions of the retarded themselves.[81] Undoubtedly they will, if indeed they are associations of the retarded themselves (this is the very subtle and complex problem of manipulation to which we shall return below).

The point is that among the organizations in coalition for purposes of using lawyers and the courts (and otherwise) should be organizations of the retarded and the handicapped themselves. If lawyers can do best what they can do only with the close participation of their clients (another matter to which we shall return below), then retarded and handicapped persons themslves, and their organizations, must be among the lawyers' clients. Thus, it is important that organizations of the retarded begin and grow. And therein lies a host of sensitive and most important questions, some of which have been raised above in the discussion of research.

In the general context of seeking the opinions of the retarded and in seeking to assist in organizing, a crucial question is: how shall situations of consultation with the retarded be structured? That is a question which Ann Shearer discusses carefully in her chapter in this volume. In the subclass of those interactions which is the retarded peron's relationship as client with hi(r) lawyer, the most sensitive and important question is the question of manipulation. That question is not uniquely present here, though it may be present here in unique form. The problem of manipulation is endemic to all lawyering and indeed to relationships of all professionals; for, by definition, "profession" means special knowledge. And special knowledge invariably presents the opportunity to control events and other persons by use of that special knowledge. Most such control we accept as benign—a teacher keeping a classroom of children orderly (though not too orderly) and at creative work; a doctor causing a person to ingest strange pink pills four times a day; a purchaser's lawyer drafting a contract which determines many of the decisions of the production manager of a plant for the next four years—but even in these benign activities the question of manipulation is implicit. Ultimately, the problem of manipulation will be removed from professional relationships with others only when that special knowledge is no longer special but fully distributed and shared in our society. The problem is diminished to the extent that special knowledge is in fact shared with the other persons. (That is the point, so seldom realized, of the homily which is so often recited by and to professionals: "Lay out the alternatives to your client, and their consequences, and (s)he will decide," though everyone also knows that what alternatives one chooses to lay out, and how, can determine the decision.) That—the extent to which special knowledge is shared in fact with the other—is also the basis of our comfort with the lawyer and for our comfort (or none) with the doctor and with the teacher. (We assume that the production manager had equal access to special knowledge and, indeed, that if relevant special knowledge was intentionally withheld from him, the contract will be void for fraud.)

But the problem is deeper even than professional "special knowledge," though it is compounded by it. In any human interaction, the exchange of meaning is of the essence.[82] And hence, there is always the opportunity and the necessity to interpret, and the opportunity to interpret not only for oneself but for the other, to persuade the other that your interpretations are really hi(r) interpretations (or beliefs or desires), and hence, to manipulate. There are no automatic rules or sanctions to eliminate manipulation. There are only skills (including observation of self) and exhortations. For professionals in relationships with clients, there are the exhortations and skills of "professional responsibility," exhortations reinforced by the probable truth that function (having what one is doing work) most often reinforces responsibility: if you have not shared special knowledge but have relied on manipulation, what you are seeking to do (or get, or be), you will probably not accomplish (or get or become).

So the question which exists in every human relationship, exists for lawyers and other professionals in their professional-client relationship with retarded persons. It is perhaps even more emphatic in relationships with retarded persons, for they are different, after all, and a part of the difference may be that they are more susceptible to manipulation. There is no magic to purge the question; it must be dealt with each day.

Roles for Clients and/or Lawyers

The analysis offered above in this paper suggests that the uses of lawyers are not merely court-oriented, and that even when their uses are court-oriented, they are not that alone, for the discharge of the lawyer's functions in court may (and must) have effect in other places as well. A lawyer, therefore, must—if he is to be effective in using the courts and, more generally, the law to contribute to the realization of the rights of his clients—include in his repertoire of roles both the directly court-oriented roles:

fact-gatherer and fact-researcher
law-knower and researcher
theory creator and adaptor
pleader
trier of facts
arguer of "the law"
designer of remedies
draftsman
negotiator
counselor

and indirectly court-oriented and otherwise oriented roles:

investigator
muck raker
social scientist
avid reader of the daily press, government reports, and professional-consumer journals
writer
publicist
dramatist
negotiator
special pleader
consultant
hard and soft sell artist
lobbyist
strategist
large-scale organization analyst
organizer and reorganizer
bureaucrat
teacher
counselor

Indeed, the second set of roles is implicit in the first and they are just as necessary to securing an order from the courts, and enforcing it, as they are to securing orders and product from the legislature and the bureaucracy and otherwise to structuring public and private orders so as to enhance the position of the lawyer's clients. (And both sets of roles must be assumed by everyone—lawyer, client, professional, parent, and handicapped person—who would participate effectively in social change.) Without the will and the ability to take on these roles, or find someone who will, the lawyer cannot function effectively.

This is not the place to explore whether and to what extent and why the law schools produce such lawyers. Some lawyers have those skills and the will, and some do not. And, of course, some lawyers who say they do, do not; some who do not say, do. The important thing is, that in staffing their Centers on Law and the Handicapped, the coalition of organizations should seek to hire those lawyers who do and not to hire (or fire) those lawyers who do not.[83]

One set of roles was left out of the listing above; it is the set of roles for clients and roles for lawyers which define the relationship between them. Put shortly and in the gross, the client's role is to be assertive and the lawyer's role is to be responsive. Roles such as initiator, listener, idea man (or woman), prober, insister, and so on, will be shared, sometimes weighted on one side and—from issue to issue, from matter to matter, from function to function, from struggle to struggle—sometimes weighed on the other, but the gestalt of the relationship will show clearly that decision-making is the role of the client.

This is as it should be, both because professional canons say it shall be so—Ethical Consideration 7-7 of the Lawyers' Code of Professional Responsibility, for example, provides: "In certain areas of legal representation not affecting the merits of the cause or substantially prejudicing the rights of a client, a lawyer is entitled to make decisions on his own. But otherwise the authority to make decisions is exclusively that of the client and if made within the framework of the law, such decisions are binding on his lawyer"—and still more important because experience in the relationship over history (memorialized sometimes in such places as Codes of Professional

Responsibility) instructs that it works best this way. It works best this way not only internally, for the relationship between client and lawyer itself, but also, and quite as important, externally, to discharge the functions assigned in the society to the professional—in the instance at hand, the uses of lawyers, the courts and the law to achieve social change and justice.

A recent study by Douglas Rosenthal, *Lawyer and Client: Who's in Charge?*,[84] confirms again that this is so, even in the kinds of disputes frequently and widely regarded as "traditionally" the province of the lawyer alone. (Though the tradition is, and long has been, to the contrary.) Rosenthal takes a close look at the preparation and trial of personal injury cases in which parties are seeking to sue the courts directly for change and finds that the "results" in those cases are "better" in a measure common to both clients and lawyers (namely dollars) when lawyer and client have shared in the development and management of the case and client decision-making has predominated.

The same differential productivity may be expected to hold in cases which seek to use the courts indirectly as well as directly for change. In such cases the second set of roles and the skills implicit in them are involved. And in these roles, lawyers, while they may sometimes be especially skillful, have no (not even a formal) monopoly. The skills necessary to this set of roles are more widely shared in the society; and clients, particularly organizational clients, will have them in significant measure. Further, since such cases in part involve diagnosing and affecting political processes other than the courts (albeit through the courts as well as otherwise), the lawyer in his solitary state (and, indeed, anyone else alone) can usually not do the job. Thus, there is even greater reason to suppose that the results will be better in these cases when there is a close relationship between lawyer and client, client decision-making predominating.

". . . They Just Fade Away"

While lawyers tend not to be retiring people, the implications of what has been said is that the use of lawyers and the courts will tend to fade as their contribution to the mobilization of forces toward change has been milked for all it's worth.

Once rights are fully realized and secured, lawyers will surely disappear, but that is the millenium. The tendency is, nonetheless, implicit in the proper role for lawyers vis-a-vis clients. It is implicit in the transmission by professionals—lawyers, in this instance—of whatever special knowlege or skills they possess to their clients, to the point that they are widely shared. It is implicit in the processes of social change themselves and in the analysis of the uses of the courts offered here. Once resources are so mobilized that organizations of handicapped persons may bargain to a satisfactory conclusion with those people and institutions and bureaucracies which affect the quality of their lives, the uses of the courts and of lawyers will have been largely exhausted and the handicapped may rely entirely on the ordinary political processes to protect their rights. There would remain for lawyers and the courts only those matters that are assigned for decision to the courts exclusively and not to other political processes (commitments, perhaps, if "commitment" could still exist at all; criminal prosecutions; the probate of estates and so on), and occasional sporadic contests with other repeat-players with whom contacts are occasional and sporadic and with whom, therefore, a satisfactory "private" bargaining process has not been established.

Thus, for illustration of the promise of things to come, the relative demise of welfare litigation in recent years may be a mark not of the failure of the use of lawyers and of the courts by welfare recipients to advance their rights, as it has been widely described,[85] but a mark of its success. After a rush of victories in the courts in the mid-1960s, the courts turned sour, decided a few cases badly and announced some rules which discouraged further suit. But by that time, it may be that forces were so well mobilized at the behest of welfare recipients that they would in any case have turned from the courts. This may well have been the case in Philadelphia; it was decidedly not in other parts of the country. A further, but less reliable, measure would be the increase in the proportion of those eligible for public assistance who are receiving it and an increase in the ratio between the level of public assistance income and the level required for a "minimum but adequate" income as calculated by the Bureau of Labor Statistics. On both measures, Welfare Rights Organizations are succeeding and the uses of lawyers and the courts (even including the losing cases) have, undoubtedly, had their place, but they have not yet succeeded and evidence is that all of their forces have not yet been mobilized. So it is with the handicapped too.

For now, in the pursuit of the rights of the handicapped, we must mobilize ourselves to use the courts and the law, and other means. As Frederick Douglass and Ocania Chalk said, "agitate, agitate, agitate." As Joe Hill said, "organize, organize, organize." Here we add, "litigate, implement, research, litigate, litigate" until we are fully mobilized, the balance of forces is changed, those who, like legislatures, say things, do them, and handicapped citizens are well on their way to rights in fact.

References

1. E. Goffman, Strategic Interaction, 3 (University of Pennsylvania Press, 1969).
2. Settled assumptions about retarded persons are challenged not only by essential ideas of humanism but also by the very significant change in the decades since the Second World War in the "fact," i.e., our understanding of the possibilities, and of the ways and means to realize them, for a full life for the retarded. See, e.g., Roos, "Trends and Issues in Special Education for the Mentally Retarded," 5 Education and Training of the Mentally Retarded, 51 (1970); Yates, Behavior Therapy, 324 (1970).

   Generally on the new technology and on criteria for judgment about who shall receive its benefits (and the detriments), see Shapiro, "Who Merits Merit? Problems in Distributive Justice and Utility Posed by the New Biology," 48 Southern California L. Rev. 318 (1974).

   As to the relationship between changing facts and the law and the courts, consider the opinion of the United States Supreme Court in *United States v. Carolene Products Co.*, 304 U.S. 144, 153 (1938):

   "The constitutionality of a statue predicated upon the existence of a particular state of facts may be challenged by showing . . . that those facts have ceased to exist."
3. Consider the constitutional career of black persons, from "three-fifths of a person" (Art. I, Sec. 2, U.S. Const. (1787)), to property *Dred Scott v. Sandford,* 60 U.S. 393 (1856)) to freedman (Art. XIII, U.S. Const. (1865)), to "equal" but separate *(Plessy v. Ferguson,* 163 U.S. 537 (1896)), to equal and integrated *(Brown v. Board of Education,* 347 U.S. 483 (1954)). The careers of women, the elderly, the poor, and the handicapped, are marked by similar traces in the law. See Gilhool, "The Rights of Citizens Who are Different to Services in the Community," Chapter 7 in Kindred, Cohen, Penrod & Shaffer, Mentally Retarded Citizens and the Law, (The Free Press, 1976). See also Stone, "Should Trees Have Standing?", 45 Southern California L. Rev. 450 (1972).
4. As later Chief justice Stone wrote for the Court in *United States v. Carolene Products Co.* 304 U.S. 144, 152-53 n.4 (1938):

   "Prejudice against discrete and insular minorities may be a special condition, which tends seriously to curtail the operation of those political processes ordinarily to be relied upon to protect minorities, and which may call for a correspondingly more searching judicial inquiry."

   See Lusky, "Minority Rights and the Public Interest," 52 Yale L.J. 1 (1942).
5. 405 U.S. 156, 164 (1972).
6. S. Scheingold, The Politics of Rights, 123 (Yale University Press, 1974). More exactly, declarations of rights are a part of (and sometimes aprelude to) political struggle. See also Gilhool, "The Uses of Litigation: The Right of Retarded Children to a Free Public Education," 50 Peabody J. of Educ. 123 (1973); J. Lippman and I. Goldberg, Right to Education; An Anatomy of the Pennsylvania Case and Its Implications for Children, 46 (1973).
7. 262 U.S. 390, 401-02 (1923).
8. Ibid.
9. *Dennis v. United States,* 339 U.S. 162, 184 (1950).
10. The best and fullest collection of essays reviewing developing legal doctrine as it seeks to make benefit of these norms available to retarded citizens in every area of their lives is Kindred, Cohen, Penrod & Shaffer. Mentally Retarded Citizens and the Law, (The Free Press, 1976) (the proceedings of the 1973 Ohio State Conference, sponsored by the President's Committee on Mental Retardation).
11. The phrase is most recently borrowed from Dellinger, "Of Rights and Remedies: The Constitution as sword," 85 Harv. L. Rev. 1532, 1534, (1972).
12. The illustration is more fully worked out, and the legal arguments upon which the claims of zero-reject education and due process rest, are reported, inter alia, in Dimond, "The Constitutional Right to Education: The Quiet Revolution," 24 Hastings L.J. 1087 (1973); "Education: An Inalienable Right,"

39 Exceptional Children 597 (1973); Gilhool, "The Rights of Citizens Who are Different to Services in the Community," Chapter 7 in Kindred, Cohen, Penrod & Shaffer, Mentally Retarded Citizens and the Law, (The Free Press, 1976); and Note, "Equal Protection and Intelligence," 26 Stanford L. Rev. 647 (1974).

The magnitude of exclusions from schooling was first publicly estimated in the Report of the Massachuetts Task Force on Children Out of School, The Way We Go to School, (Beacon Press, 1970). Estimates for the country as a whole have now been carefully compiled and analyzed by the Children's Defense Fund, Washington, D.C. in its Report, Children Out of School in America (1974).

13. For two excellent discussions of the uses and functions of the due process hearing, see Dimond, "The Constitutional Right to Education: The Quiet Revolution," 24 Hastings L.J. 1087 (1973) and Kirp, Buss & Kuriloff, "Legal Reform of Special Education: Empirical Studies and Procedural Proposals," 62 California L. Rev. 40 (1974). The latter assesses in preliminary fashion, the impact of the *PARC*, 343 F. Supp. 279 (E.D. Pa. 1972), *Mills*, 348 F. Supp. 866 (D.D.C. 1972), and *Diana*, and *Larry P.*, 343 F. Supp. 1306 (N.D. Cal. 1972) cases. A later report, Kuriloff, True, Kirp & Buss, "Legal Reform and Educational Change: 1 The Pennsylvania Case," 41 Exceptional Children 35 (1974) updates some of the qualitative measures of impact (e.g., by this time 16 months after the final order in *PARC*, 13,000 previously out-of-school retarded children had been admitted to public schooling). Further reports on this impact assessment project will be forthcoming.

The possibilities for the use of such hearings may be seen by looking to the impact of similar hearing mechanisms in similar areas, such as public assistance and public housing, See, e.g., Lempert, "Evictions from Public Housing: Effects of Independent Review," 35 American Sociological Rev. 852–60 (Oct. 1970). C.F., Dauer & Gilhool, "The Economics of Constitutionalized Repossession," 47 So. Cal. L. Rev. 116, 138–150 (1973).

In Philadelphia, for example, the selective use of the Social Security Act hearing mechanisms by the Philadelphia Welfare Rights Organization, coupled with "collective bargaining" between PWRO and the County Director of Public Assistance pursuant to a "recognition" agreement, and intensive representation of complainants by PWRO in informal negotiations short of the hearing (see the discussion of local task forces in the text) resulted in a drop in the rate of rejections of applications for public assistance from nearly 50 percent to 25 percent in a year and a half. See Gilhool, "The Uses of Litigation," 2 Leadership Series in Special Education, 167 (U. of Minn. 1973). Questions of appropriateness of education undoubtedly will present opportunities and problems in some degree different from those presented by eligibility decisions for public assistance; but that and similar experience may be nonetheless instructive.

14. Compare *Area Wide Council v. Romney*, 456 F.2d 811 and 469 F.2d 1326 (3d Cir. 1972), holding that the requirement of "maximum feasible participation" in the Model Cities Act requires "good faith bargaining" with low-income residents of the area, a duty whose content is drawn by analogy from the National Labor Relations Act.

15. 42 U.S.C.A., sec. 2674.

16. 20 U.S.C.A., sec. 1231d.

17. These range all the way from the right to speak (but not necessarily to be listened to or heeded) in a public forum at planning stages of urban renewal projects to a right of veto on certain issues accorded Project Area Committees in Neighborhood Renewal Programs. For the tale of one recognition agreement and collective bargaining model, built on a requirement of tenant participation as a condition of funds for public housing modernization, see "Public Housing: Tenant's Role," 28 J. of Housing 413 (1971).

18. *Wyatt v. Stickney*, 344 F. Supp. 387, 392 (M.D. Ala. 1972), affirmed sub. nom., *Wyatt v. Aderholt*, 503 F.2d 1305 (5th Cir. 1974).

19. Schiengold, The Politics of Right, 123 (Yale Univ. Press, 1974).

20. Warren, "The Notre Dame Law School Civil Rights Lectures," 46 Notre Dame Lawyer 14, 16–17 (1972).

21. Bickel, The Least Dangerous Branch: The Supreme Court at the Bar of Politics, esp. Chapter 6 (1962).
For an intriguing discussion of a, perhaps, contrasting "activist," patience-exhausted possibility (that a court may order Alabama to sell off the land surrounding its institutions to finance treatment for its residents), see *Wyatt v. Aderhold,* 503 F.2d 1305, 1316–19 (5th Cir. 1974).
22. 29 U.S.C.A., sec. 793 (Supp. 1974).
23. 401 U.S. 424, 431 (1971).
24. For a full discussion of Section 503, see the forthcoming Note, "Affirmative Action in Hiring Handicapped Persons," 48 Southern California L. Rev. (1976): Weiss, "Equal Employment Opportunity and the Disabled," 10 Col. J. of Law & Social Problems, 457 (1974).
25. Conley, The Economics of Mental Retardation, 336 (Johns Hopkins Univ. Press. 1974). Indeed Conley's estimate was avowedly conservative, see pp. 332–53.
26. *King-Smith v. Aaron,* 455 F.2d 378 (3d Cir. 1972).
26*a*. The cases are unreported in the law reports because they were favorably settled before court decision, but they have been extensively reported in the popular media and the media of organizations of the handicapped.
27. The Council for Exceptional Children, Arlington, Virginia, maintains a continuing summary of such acts of legislatures and of the courts.
28. See, e.g., Dahl, Who Governs? (Yale Univ. Press, 1961); and Lane, Political Life (Yale Univ. Press, 1964).
29. Kay Gorham, "The Parent's Perspective on the Law," paper delivered at the National Conference on the Mentally Retarded Citizen and the Law sponsored by the President's Committee on Mental Retardation, May 3–5, 1973, Columbus, Ohio.
30. Closer Look, Winter, 1975. (Box 1492, Washington, D.C. 20013).
31. S. R. Gelman, "Periodic Review of Mentally Retarded Residents," 19 Social Work 726 (1974) and Kirp, Buss & Kuriloff, "Legal Reform of Special Education: Empirical Studies and Procedural Proposals," 62 California L. Rev. 40 (1974) are almost alone in looking carefully at the impact of recent developments. Kirp, et al., is discussed at Footnote 13. Gelman assesses the impact of annual or periodic review of residents of state institutions and concludes "the reform legislation has done little to alter the institutional power base—power remains concentrated at points other than local communities. New legislation without a firm administrative base, without adequate funds for staffing and support systems needed for implementation, without the necessary planning and coordination, and without effective links to other service systems, cannot go far toward changing our present institutional system."
32. See the New York Times series on nursing homes for the elderly, October, 7, 8, and 10, 1975, and reports of the continuing investigation thereafter.
33. Galanter's paper, Working Paper No. 7, in the Yale Law School Program in Law and Modernization (1972), is published at 9 Law & Society Rev. (1974).
Galanter's distinction between "repeat-players" and "one-shotters" has deep roots in sociological thought. Similar distinctions, to different purposes but quite as fruitful, have been invoked by Leff, "Injury, Ignorance and Spite—The Dynamics of Coercive Collection," 80 Yale L.J. 1, 19–26 (1970) (distinguishing the "consumer as creditor" from the "professional as creditor" to analyze the dynamics of the American collection system) and MacNeil, "The Many Futures of Contracts," 47 So. Cal. L. Rev. 691, 737–744 (1974) (distinguishing "transactional" interactions from "relational" interactions to analyze problems of choice and contract).
34. Galanter, supra, pp. 6-7.
This analysis explains the great difficulties in getting any justice at all (or at best random justice), let alone the seeming imposibility of getting favorable rules changes in criminal or juvenile prosecutions against handicapped persons, and in commitment proceedings. See, e.g., Cohen, "The Function of the Attorney and The Commitment of the Mentally Ill," 44 Texas L. Rev. 424 (1966). A great deal of fine doctrinal work has been done in these "defensive" areas; e.g., Allen, Firster & Weihofen, Mental Impairment and Legal Incompentency (Prentice-Hall, 1968); Brakel & Rock, The Mentally Disabled and the Law (U. of Chicago Press, 1971); but not

much can be effectively done for individual parties who find themselves in these suits until and unless we are able to handle their defenses systematically as repeat-players would, to lend to them, as it were, the benefits of repeat-player-hood, and to translate their defensive posture into an offensive one.

35. Galanter, supra at pp. 35–36. Schiengold's analysis, The Politics of Rights (Yale Univ. Press, 1974), is not dissimilar. Schiengold, however, misses the possibility of the repeat-player. His analysis is partially flawed by a too simple conception of the relationship of organizations to litigation.
36. Galanter, supra, at p. 30.
37. Goulden, The Superlawyers: The Small and Powerful World of the Great Washington Law Firms, 32–37 (Weybright & Talley, 1971). On the consequences—ill—of this most effective use of the law, see Levine, "Is Regulation Necessary? California Air Transportation and National Regulatory Policy," 74 Yale L.J. 1417 (1965).
38. Empirical work on the impact of WRO's and their lawyers is scarce, but the story may be garnered from Sparer, "The Right to Welfare," in Dorsen (ed.), The Rights of Americans (Pantheon, 1971); Cloward & Piven, Regulating the Poor (Pantheon, 1971).

    Generally on the impact of poverty lawyering, see Johnson, Justice and Reform, esp. Chapter 8 (Russell Sage, 1974). The Philadelphia experience is discussed in Gilhool, "The Uses of Litigation," 2 Leadership Series in Special Education, 167 (U. of Minn., 1973).
39 The story is told, among other places, in Greenberg, "Litigation for Social Change: Methods, Limits and Role in Democracy," 29 The Record of the Assoc. of the Bar of the City of New York (April 1974). For a systematic look see Vose, "Litigation as a Form of Pressure Group Activity," 319 Annals of the Am. Academy of Polit. & Soc. Sci., 20 (1958); Vose, Caucasians Only: The Supreme Court, the NAACP, and the Restrictive Covenant Cases (U. of California Press, 1967). C.F. Comment, "Private Attorneys General: Group Action in the Fight for Civil Liberties," 58 Yale L.J. 574 (1949).
40. For social change work a lawyer fresh out of law school can be hired for about $11,000; a lawyer of four to six years experience, for about $21,000; and a lawyer of ten years experience, for about $27,000. Those figures obtain in major metropolitan areas, and may be less in some other areas of the country. Thus, staff lawyers can be engaged at about the same price as other retardation professionals.
41. The "optimum," for a three-lawyer office, will include one senior, one mid-level, and one beginning lawyer.
42. A prototypical rights handbook is Biklen, "Let Our Children Go: An Organizing Manual for Advocates and Parents," (Human Policy Press, Syracuse Univ., 1974). Closer Look (see its Winter 1975 issue), is collecting handbooks produced across the country and making them available to all who ask for them. The handbook strategy was widely and well used by Welfare Rights Organizations. See the papers cited above at Footnote 38.
43. Indeed, the coalition might productively extend to other citizens who are different—to the elderly, who share with the handicapped common problems of access to transportation, and control of the quality of nursing homes (which problems arise from the same sources and respond to similar remedies); and to the poor, who share common problems of access to income, to employment, and to health care; and to blacks and the elderly and women, who share the common opportunity to be different and the common problem of rearranging services and power so that each may be what (s)he chooses to be.
44. Developments in the use of volunteer lawyers, and in illustrations of effective and ineffective ways and means of using them, are reported periodically in the Pro Bono Report, published by the American Bar Association's section on Individual Rights and Responsibilities.
45. On the award of attorneys fees by the courts, see, e.g., *Newmann v. Piggie Park Enterprises*, 390 U.S. 400 (1968); and *La Raza Unida v. Volpe*, 57 F.R.D. 94 (N.D. Cal. 1972). The cases on attorneys fees are collected and analyzed in M. F. Derfner, "Attorneys Fees in Pro Bono Publico Cases: A Compilation of Federal Court Cases", available (for $7.00) from the Lawyers' Committee for Civil Rights Under Law, Washington, D.C.

A recent decision has introduced some uncertainty into the law of attorneys fees. The Supreme Court recently held that federal courts are not authorized to award attorneys fees to a plaintiff winning an injunctive action merely on the "private attorney general" theory. *Alyeska Pipeline Service Co. v. Wilderness Society,* 95 S. Ct. 1612 (1975). But the Court explicitly recognized many situations in which attorneys fees may be awarded: where the losing party has acted in bad faith, vexatiously, wantonly, or for oppressive reasons; where the winning party has preserved or recovered a fund or property on behalf of others in addition to hi(r)self; or where, as in antitrust and civil rights cases. Congress has provided by statute for such fees. (95 S. Ct. at 1622–23). Furthermore, the ruling will presumably not prevent the parties to an action from agreeing to a standard for award of fees as part of a larger settlement, which agreement would then be enforceable in court (see, e.g., *Arenson v. Chicago Mercantile Exchange,* 372 F. Supp. 1349 (N.D. Ill. 1974). And, of course, the decision does not affect the award of fees in the state courts.

46. Under a wide variety of sponsorship, there have recently been established an equally wide variety of group legal services plans, analogous to health insurance, to make legal services available to middle-income persons at a low cost. The most interesting and the most hopeful of these plans are under the sponsorship of labor unions, which in coalition with bar and consumer groups have recently secured an amendment to the Taft-Hartley Act permitting collective bargaining for legal services benefits, as now there is bargaining for health and retirement benefits. While few of these plans have yet made provision for social change litigation, many unions have long since been very active on behalf of the handicapped, whether relatives of members or not. One may hope, therefore, that group legal services plans will make lawyers available to secure the rights of the handicapped. Developments in group legal services are reported periodically in Group Legal Review, published by the National Consumer Center for Legal Services, Washington, D.C. Developments in legal services for middle income persons, for the poor, in public interest and in the structure of the legal professions generally are reported periodically in Trends in Legal Services, published commercially by Editorial Services, Washington, D.C.

47. The instrumentalities responsible for most of the litigation on behalf of the handicapped to this date—Legal Services Programs for the poor, formerly funded through the Office of Economic Opportunity, and funded now by a recently created federal corporation, the National Legal Services Corporation—remain in trouble. The prospects of Legal Services Programs will be determined by the members of the new Corporation's Board and by the regulations they write. The Corporation bill passed by the House provided that special emphasis be given to representation of the handicapped; that provision was deleted by the Senate, though the Conference Report, but not the Act, contains a similar emphasis. Developments in legal services for the poor are reported periodically in The NLADA Briefcase, published by the National Legal Aid and Defender Association, Washington, D.C., and in the National Clearinghouse Review, a reporter system for poverty lawyers, published by the National Clearinghouse for Legal Services, Northwestern University School of Law, Chicago, Illinois.

The second instrumentality signifcantly responsible for the litigation on behalf of the handicapped to date is the network of "public interest law firms" which dots the country. Typically, these are foundation-funded law firms, sometimes associated with the Lawyers Committee for Civil Rights Under Law and the NAACP Legal Defense Fund. Developments in this part of the profession may be followed through the newly created Center for the Advancement of Public Interest Law, Washington, D.C. The special tax status of these firms, a status which Centers on Law and the Handicapped would share, is discussed in B. Heineman, Jr. In Pursuit of the Public Interest, 84 Yale L.J. 182, 198 (1974), and Hearings on Tax Exemptions for Charitable Organizations Affecting Poverty Programs, Subcommittee on Employment, Manpower and Poverty of Senate Committee on Labor and Public Welfare, 91st Congress, 2d Session (November 16 and 17, 1975).

48. The tale of the employees is told in *Wyatt v. Aderholt,* 503 F.2d 1305, 1307-09, affirming *Wyatt v. Stickney,* 344 F. Supp. 390 (M.D. Ala., 1972).
49. *Parrish v. Civil Service Commission,* 66 Cal. 2d 260, 425 P.2d 223 (1967).
50. *Chalk Appeal,* 441 Pa. 376 (1971).
51. *Donahue v. Staunton,* 471 F.2d 475 (7th Cir. 1972), cert. denied, 410 U.S. 955 (1973).
52. 493 F.2d 507, 518 and 527 (5th Cir. 1974). This case is now pending in the United States Supreme Court.
53. *McClelland Appeal,* Pa. Civil Service Commission No. 1423 (October 25, 1973) reversed on other grounds sub. nom., *McClelland v. Civil Service Commission* 322 A.2d 133 (Pa. Cmwlth, 1974).
54. The definition is from Webster's New International Dictionary 1713 (1923; professional canons of ethics are reviewed in D. Rosenthal, Lawyers and Clients: Who's in Charge? (Russell Sage 1974); and the nature of professions is analyzed in T. Parson, Professions, Internat'l Encyclopedia of Social Science.
55. The California provision may be found at 15 Cal. Health & Safety Code, sec. 1501 (1974); the Pennsylvania provision, at Pa. Stat. Ann., Tit. 50, sec. 4201 (1969). Similar provisions dot state codes on education, welfare, housing and recreation.
56. E.g., Louisell & Hazard, Pleading and Procedure, 196 (Foundation Press, 3d Ed., 1973).
57. The quoted phrases are from later Chief Justice Stone writing for the Supreme Court in *United States v. Carolene Products Co.,* 304 U.S. 152–53, n. 4 (1938). His text is set out in full at Footnote 4, supra.

    It is Hazard's failure, in "Social Justice Through Civil Justice," 36 U. Chicago L. Rev. 699 (1969), to take account of the possibility of repeat-players (his model for litigation is basically a one-shot private party against another one-shot private party), of the uses of litigation for mobilization and for the influence of court declarations in other political arenas, and of the contingent costs and advantages of the use of a particular method of petition (or dispute resolution, or dispute creation) rather than another depending upon one's social situation that accounts for his grim, and erroneous, conclusions about the uses of litigation to secure redistribution. To be sure, Hazard sometimes switches to a model of litigation as one-shot private party against repeat-player private party, but even then the other two omissions vitiate his analysis. Further, Hazard's definition of distributive justice is considerably narrower than Artistotle's. For Aristotle, distributive justice was concerned with "distributions of honour or money or other things that fall to be divided among those who have a share in the constitution, "Ch. 2, Bk. V., Nicomachean Ethics.

    For Hazard, it is merely "allocation of community resources," Ibid., 704.
58. See, e.g., G. Calibresi, The Costs of Accidents (Yale Univ. Press, 1970); R. Keeton, Legal Cause in the Law of Torts (Ohio State, 1963).
59. For suggestive bibliographies on the design and execution of impact studies, see Wasby, The Impact of the United States Supreme Court, 283–291 (Dorsey Press, 1970) and T. Becker, The Impact of Supreme Court Decisions: Empirical Studies (Oxford Univ. Press, 1969).

    Footnote 30, supra, cities two excellent studies by Gelman & Kirp and Buss & Kuriloff, among the few concerned with the rights of the handicapped.
60. The Southern California L. Rev. Note parsing Section 503 and suggesting standards for its enforcement is cited at Foonote 24, supra.
61. See Conley, The Economics of Mental Retardation passim (Johns Hopkins Univ. Press, 1974).
62. The best explication of this strategy and the assumptions which undergird it is Dimond, "The Constitutional Right to Education: The Quiet Revolution," 24 Hastings L. J. 1087 (1973).
63. The Social Security Act provision is at Title 42 U.S.C., sec. 602(a)(10) (Adopted in 1950). The cases are *King v. Smith,* 392 U.S. 309, 333 (1968); *Townsend v. Swenk,* 404 U.S. 282, 285–86 (1971); *Carleson v. Remillard,* 406 U.S. 598, 600 (1972).
64. See, e.g., Burt, "Beyond the Right to Treatment," in Kindred, Cohen, Penrod & Shaffer, Mentally Retarded Citizens and the Law (The Free Press, 1976).
65. Order of March 2, 1973.
66. *Wyatt v. Stickney,* did declare, "Residents shall have a right to the least restrictive conditions necessary to achieve the purposes of habilitation," and that the institution might implement the "principle

. . . that each resident may live as normally as possible." "Every attempt" was to be made to move residents from large structured, isolated living units as far as possible toward autonomous living in the community. 344 F. Supp. 373, 396 (Minimum Constitutional Standards 2, 3c).

67. *Wyatt v. Aderholt,* 503 F.2d 1305, 1316–17 (5th Cir. 1974).

68. In four years residents (net) in California's hospitals for the developmentally disabled were released. Annual institutional expenditures by the state were reduced by $42 million, but at the end of that four years, annual expenditures for mental health services in the community had increased by only $4 million. The Governor's Budget, Health and Welfare Supplement 1974–75. To be sure, many of the residents released were undoubtedly not mentally ill at all, see B. Ennis & T. Litwack, Psychiatry and the Presumption of Expertise: Flipping Coins in the Courtroom, 62 California L. Rev. 693 (1974), and the figures above do not reflect services delivered in the community but accounted in the budget in generic program expenditures.

For an excellent account of California's ill-managed institution-closing program (an account not nearly so grim as popular expectation has it), see the Report of the Senate Select Committee on Proposed Phaseout of State Hospital Services, Sen. Alfred E. Alquist, Chairman (Paul O'Rourke, consultant) (1974).

69. *United States v. Carolene Products Co.,* 304 U.S. 144, 153 (1938).

70. For the arguments made—but not yet authoritatively adopted—for such general rights, see F. Michelman, "Supreme Court, 1968 Term. Foreword: On Protecting the Poor Through the Fourteenth Amendment," 83 Harv. L. Rev. 7 (1969), and F. Michelman, "In Pursuit of Constitutional Welfare Rights: One View of Rawls' Theory of Justice," 121 U. Pa. L. Rev. 962 (1973).

For a discussion of the relevant cases, especially *Dandridge v. Williams,* 397 U.S. 471, 480–81 (1970) and *Jefferson v. Hackney,* 406 U.S. 535, 540–41 and N.S. (1972) (income) and *Lindsey v. Normet,* 405 U.S. 56, 74 (1972) (housing), and their reservation of the question of general rights, see Gilhool, "The Rights of Citizens Who are Different to Services in the Community," at Footnote 29 therein, Chapter 7, in Kindred, Cohen, Penrod & Shaffer, Mentally Retarded Citizens and the Law (Free Press, 1976).

71. E.G., *San Antonio School District v. Rodriguez,* 411 U.S. 1, 36–37 (1973) (dictum: "Some identifiable quantum" of education may be constitutionally guaranteed to all). See Dimond & Reed, "*Rodriguez* and Retarded Children," 2 J. of Law & Education 476 (1973). For a general typology of services elaborating claims of rights, see Gilhool, "The Rights of Citizens Who are Different to Services in the Community," at Section II, Chapter 7 in Kindred, Cohen, Penrod & Shaffer, Mentally Retarded Citizens and the Law (Free Press, 1976).

72. See this paper, supra, at Footnote 43.

73. The *Larry P.* case is reported at 343 F. Supp. 1306 (N.D. Cal. 1972); *Diana* is unreported. The misclassification cases are discussed in Kirp, Buss & Kuriloff, "Legal Reform of Special Education: Empirical Studies and Procedural Proposals, "62 Cal. L. Rev. 40, 96–112 (1974) and in Kirp, "Schools as Sorters: The Constitutional and Policy Implications of Student Classification," 121 U. Pa. L. Rev. 705 (1973).

74. See, e.g., N. Hobbs, The Futures of Children, (Jossey-Basse, 1974).

75. Reported, among other places, in R. Edgerton, The Cloak of Competence (U. of Cal. Press, 1967).

76. See Ann Shearer's chapter herein. And see, e.g., W. B. Stephens, "The Development of Reasoning, Moral Judgment and Moral Conduct in Retardates and Normals. Phase II. Final Report." Cooperative Project #RD 2382P (Temple Univ., 1972).

77. *Shields v. Barrow,* 58 U.S. 130, 139 (1854).

77*a*. *Wisconsin v. Yoder,* 406 U.S. 205, 241, 243, 244–5 (1972). Generally, see Goldstein, Freud & Solnit, Beyond the Best Interests of the Child, Chapter 5 (MacMillan, 1973).

78. *Horacek v. Exon,* 357 F. Supp. 71, 74 (D. Neb. 1973).

79. *Saville* v. *Treadway* (M.D. Tenn., Civil Action No. 6969, March 8, 1974) (unpublished opinion); *Bartley v. Cremins* (E.D. Pa., Civil Action No. 72–2272, July 24, 1975). Generally, see Ellis, "Volunteering Children: Parental Commitment of Minors to Mental Institutions," 62 Cal. L. Rev. 840 (1974); and Ferleger, "Loosing the Chains: In-Hospital Civil Liberties of Mental

Patients," 13 Santa Clara Lawyer 367 (1973).

80. It is a cultural artifact, not a legal one (though it may arise from the legal subculture). Persons are guaranteed the right, by and large, by the law to represent themselves in court. See, e.g., *Dioguardi v. Durning*, 139 F.2d 774 (2d Cir. 1944) and *Faretta v. California*, 43 L.W. 5004 (U.S., 6/30/75). And compare, Wexler, "Practicing Law for Poor People," 79 Yale L.J. 1049 (1970). The court in *Horacek* was constrained by one legal provision, Rule 17(c) of the Federal Rules of Civil Procedure, concerned with inputs of "incompetent" persons:

   > "Whenever an infant or incompetent person has a representative, such as a general guardian, committee, conservator, or other like fiduciary, the representative may sue or defend on behalf of the infant or incompetent person. If the . . . person does not have a duly appointed representative he may sue by his next friend or by a guardian ad litem. The court shall appoint a guardian ad litem for a . . . person not otherwise represented in an action or shall make such other order as it deems proper for the protection of the . . . person."

   Parents typically serve as "next friends" of any party children.

81. See Ann Shearer's chapter, "The Handicapped Person," herein. Note that the Human Rights Committee appointed in *Wyatt v. Stickney*, 344 F. Supp. 373, 376, 386 (M.D. Ala. 1972) included one mildly retarded resident of the institution. And consider that the jury studies establish that one in a group of twelve is not a sufficient critical mass to expect that that one will express hi(r)self or stand by hi(r) opinions to the contrary. Kalven & Zeisel, The American Jury, 463 (Little, Brown & Co., 1966).

82. In the exploding literature on the central places of the exchange of meaning and on reading meaning, and communicating it, the works of E. Goffman, e.g., The Presentation of Self in Everyday Life (Doubleday, 1959); Encounters (Bobbs-Merrill, 1961); Strategic Interaction (U. of Pa. Press, 1969); Relations in Public (Basic Books, 1971); are among the most trenchant.

83. That lawyering in "the grand manner" has traditionally encompassed the full set of roles (though not always for the good) is evidenced in the stretch of reports from L. Brandeis, "The Opportunity in the Law," 39 American L. Rev. 555, 559 (1905), through J. C. Goulden, The Superlawyers: The Small and Powerful World of the Great Washington Law Firms (Weybright & Talley, 1971).

   Among the excellent ruminations on role, see E. and J. Cahan, "Power to the People or the Profession?," 79 Yale L.J. 1005 (1970); A. Platt and R. Freedman, "Limits of Advocacy," 115 U. Pa. L. Rev. 1156 (1968); note, "The New Public Interest Lawyers," 79 Yale 1069 (1970); A. Matthews and J. Weiss, "What Can Be Done: A Neighborhood Lawyer's Credo," 47 B.U.L. Rev. 231 (1967); S. Wexler, "Practicing Law for Poor People," 79 Yale L.J. 1049 (1970); and E. Sparer, "The Right to Welfare," in N. Dorsen, The Rights of Americans, (Pantheon, 1971).

84. D. E. Rosenthal, Lawyer and Client: Who's in Charge? (Russell Sage, 1974).

85. See, e.g., S. Krislov, "The OEO Lawyers Fail to Constitutionalize a Right to Welfare: A Study in the Uses and Limits of the Judicial Process," 58 Minn. L. Rev. 211 (1973). And see Sparer, "The Right to Welfare," in N. Dorsen (ed.), The Rights of Americans, (Pantheon, 1971).

Biography

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Mr. Gilhool practiced law with Dilworth, Paxson, Kalish, Levy and Coleman in Philadelphia and as consumer advocate and director of law reform at Community Legal Services, Inc. in Philadelphia. In the latter capacity, he represented the Philadelphia Welfare Rights Organization, the Residents Advisory Board of Philadelphia (a public housing tenants organization) and argued the Public Assistance Residence Requirement Care (*Shapiro v. Thompson*, 394 U.S. 618 (1969)) in the United States Supreme Court. He was founding co-director of the Legal Services Training Program.

Mr. Gilhool graduated from Lehigh University in Bethlehem, has an M.A. in political science from Yale University, and his LL.B. from Yale Law School where he was an editor of the Yale Law Journal. He studied philosphy at Yale as a Woodrow Wilson Fellow and town planning at the London School of Economics as a Fulbright Scholar.

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11. The Universities

James Clements

Introduction

Massive changes in social systems are rarely due to single isolated factors. Change and new systems are usually created, accelerated and perpetuated by a series of factors, including resources. A need for change in systems for the care, treatment and training of the mentally retarded is highlighted dramatically by *Christmas in Purgatory*[1] and ordered by *A Proposed Program for National Action to Combat Mental Retardation*.[2] The assembly of national, state and local resources, beginning with President John F. Kennedy's address to Congress on mental health and mental retardation, culminated in two major legislative actions—Public Law 88–164[3] and Public Law 88–156.[4] These two congressional acts committed universities, more than ever before, to become a vital force in the changing patterns in residential services for the mentally retarded, and provided resources for them to do so.[5]

These whispers of beginnings of change, unpredictably, were to be accelerated and radically altered by conceptual forces from both within and without the university network. The principle of *Normalization*,[6] the *Cost-Benefit Management Concept*,[7] the *Free-Choice Principle*,[8] the *National Mandate for Deinstitutionalization*,[9] the *Civil Rights Movement for the Mentally Handicapped*,[10] tied with the revision of Public Law 88–164 by Public Law 91–517,[11] replacing the term "clinical training" with the term "interdisciplinary training," blended disparate forces in a whirlwind impact on the role of the universities in the field of mental retardation.

The Universities—Agents for Change—Objects of Change

The very nature of mental retardation, the multiplicity of associated factors and and conditions, worked against concentrated efforts in the universities in this field. This is not to say that universities and scholars within them have not made major contributions in the prevention, care and treatment of the mentally retarded.[12, 13] Rather, they have created a multiplicity of knowledge and methodologies, but with the exception of the area of special education, this has not been well disseminated. Effort has also not been coordinated.

The university-affiliated facilities (UAFs) were conceived as clinical facilities attached to institutions of higher education (generally universities) to perform three main functions:

1. Provide clinical training of physicians and other specialized personnel to serve those who are mentally retarded.
2. Demonstrate new techniques (exemplary services) to diagnose, treat, educate, train and care for mentally retarded persons.
3. Provide inpatient and outpatient services for mentally retarded individuals.[14]

Subsequent legislation mandated but did not define "interdisciplinary training"[15] of professionals who would learn and work as a team, a symbiosis of service to retarded persons.

The UAFs, along with the factors delineated above, have cast the universities as both objects of and agents of change in the field of mental retardation. For the purposes of this chapter, the role of the universities in the change process will be limited to a discussion of the role of the UAFs.

The UAFs—Their Concept and General Nature

As defined by the original legislation, the UAFs are a part of or affiliated with universities. For the most part, they at first tended conceptually to mimic university clinical departments.[16] By current mandate the UAFs have four distinct roles:

1. To train administrative, professional, technical, direct-care and other specialized personnel to work with mentally retarded and developmentally disabled individuals.
2. To demonstrate a full range of exemplary services which should be available to the population.
3. To conduct the necessary research to do this.

4. To assist the regions, states and communities to reach their respective objectives.[17]

First and foremost the UAFs are generally thought to be resources for providing interdisciplinary training. The vital role of demonstrating and providing services, research, and technical assistance is generally little known and poorly understood in this "new breed" of facility whose average operational life span is barely five years.

Caspar W. Weinberger, then Secretary of the Department of Health, Education, and Welfare, speaking at the John F. Kennedy Institute in Baltimore, remarked:

" . . . The University-Affiliated Centers funded by HEW have achieved reputations for excellence, innovation, and creative responsiveness. And, because of the flexibility of the program, each one provides a different thrust or emphasis.

"What is unique and important about the University-Affiliated Facilities is not their uniformity but their diversity; not their singleness of purpose, but their multiplicity of purpose."

This diversity of the UAFs is due in part to their legislative history and multiplicity of funding sources. In addition to state, local, and foundation financial resources,[18] the UAFs receive support from programs administered by the Department of Health, Education, and Welfare. Over half of UAF federal funds are derived from three agencies:

1. The Bureau of Community Health Services, Health Services Administration (formerly Maternal and Child Health Service).

2. The Division of Developmental Disabilities, Social and Rehabilitation Service.

3. The Bureau of Education for the Handicapped, Office of Education.

As a result, certain broad patterns (types) seem to be emerging with immediate impact on residental services:

1. Those with strong interlocking administrative relationships with state residential facilities.

2. Those that provide with the UAF facility certain functions for residential facilities; i.e., screening and referral.

3. Those that provide services for residential facilities within the residential facility; i.e., ongoing inservice training programs for residential care staff.

4. Those that are university-oriented and whose functions are carried out within the confines of the University and related to typical university programs; i.e., training and research.[19]

Despite their diversity in funding, site and administrative orientation, notable similarities, other than interdisciplinary training, begin to emerge. Most UAFs provide:

1. Day care for the developmentally disabled.

2. Evaluation of handicapped people and appropriateness of community resources available.

3. Medical diagnosis.

4. Behavioral and medical treatment.

5. Personal and domiciliary care.

6. Training and education.

7. Instruction in self-help skills.

8. Employment assistance.

9. Socio-legal and other protective services.

10. Recreation.

11. Counselling for the developmentally disabled and their families.

12. Progress reports to referring agencies.

13. Follow-up services.

14. Technical assistance to institutional and community programs and to State Developmental Disabilities Councils.[20]

Data collected in 1972 and 1973[21] from 33 UAFs, basically for a one-year period, reveal that:

1. 19,702[22] persons were served by 28 UAFs. During the same reporting period, 52,854 professionals and paraprofessionals were trained at 32 facilities.

2. Professionals trained were primarily in special education, nursing, pediatrics, psychology, genetics, audiology, speech pathology, nutrition, occupational therapy, social work, and home economics.[23]

3. The most frequent academic affiliations were pediatrics, speech pathology, psychology, social work, special education, and physical therapy. Two-thirds of all UAFs reporting also had affiliations in psychiatry and dentistry. More than 60 discipline affiliations were reported.

4. Community affiliations were reported by all UAFs. These affiliations were most commonly with

schools, state hospitals, child development centers, State Developmental Disabilities Councils, and nonprofit associations.

5. 29,441 trainees were candidates for degrees or board certification; 10,155 were private practitioners; 4,371 were students at a level lower than the Associate of Arts degree level.

6. The largest number of trainees (13,457) were at the baccalaureate level; 7,694 were at the doctoral level and 6,731 were at the master's level.

7. The majority of trainees (29,515) received zero to eight hours of UAF training; 2,436 trainees received more than 160 hours of training.

8. Twenty-five percent of the trainees were already employed but were seeking additional skills.

Vignettes

The purpose here is to highlight a few of the UAFs, their activities that are representative of the UAFs in general, and to point out activities that demonstrate some of the less well known programs of the UAFs. There has been no effort so far in this chapter to point out the activities or contribution of the mental retardation research centers (MRRC's) or to demonstrate the close and cooperative working relationships between the UAFs and the MRRCs.[24] There are 12 MRRCs, the majority at universities that also have UAFs and are sometimes under the same direction. It is often difficult to specifically delineate the contributions of each (UAF and MRRC) as their efforts frequently are combined, one elaborating and enhancing the other. It should also be noted that the majority of the MRRCs have a direct working relationship with residential programs—either residential institutions or community residential facilities.

Much of the cooperative research and training has a direct impact on the quality of life and methodologies of programming in these residential facilities.

The Eunice Kennedy Shriver Center at Waltham, Massachusetts

This UAF and MRRC are located on the grounds of the Walter Fernald State School for the Mentally Retarded. Major affiliations are with Harvard University and the Massachusetts General Hospital and main goals are interdisciplinary training and research with a biomedical emphasis. Objectives are directed toward improved outpatient and residential services—both within the institution and in the community. Major studies have included:

1. Behavior modification for improving the performance of severely and profoundly retarded people.

2. Placement of severely and profoundly retarded people back into the community and evaluation of the results.

3. Development of language skills and reading ability in moderately retarded individuals with Down's Syndrome.

4. An organizational study of the effects of the "unit" system within the institution and its effect on programming.

5. Behavioral profiles on the population as a basis for program planning and community placement.

The Waisman Center on Mental Retardation and Human Development, Madison, Wisconsin

Both a UAF and a MRRC are located at the University of Wisconsin.[25,26,27,28] The UAF represents the combination of a university-based program with an inpatient unit which is an extension of the Central Wisconsin Colony, a state residential facility. Emphasis is on interdisciplinary training and research, both biomedical and behavioral. Noteworthy programs directed at residential care are:

1. A rehabilitation unit which develops new technology in education and rehabilitation.

2. Behavioral studies for modification of self-mutilation, head-banging and other disturbed behaviors of severely multihandicapped children.

3. Development of foster and group home placements.

4. A cross-modality training program (the joint effort of Central Colony and the University of Wisconsin) which is now used extensively in the care, treatment and management of physically handicapped people.

5. An in-service training program for the personnel of group living homes, the community services staff of three residential facilities, and the staff of selected community-based generic health, education, and welfare agencies, and community supportive services.[29]

6. A communication disorders section to train graduate students to provide services to the severely and profoundly impaired persons in both residential and day programs.

7. Assisting residential facilities to provide needed skills to residents to cope more effectively with problems encountered in the community as they leave the institution.

Division for Disorders of Development and Learning, The University of North Carolina, Chapel Hill

This is an interdisciplinary professional training program which is administratively part of the Biological Sciences Research Center of the Child Development Research Institute.[30] There are relationships with 27 schools and departments within the university. Emphasis is on regional diagnostic and treatment services for the developmentally handicapped and their families. Programs of note are:

1. Development of community alternatives leading to deinstitutionalization.

2. Regional plan for deinstitutionalization in 16 North Carolina counties.

3. Development of two group homes.

4. Direct assistance to staff at Murdoch Center, a state residential facility, to develop a more humane environment.

5. Consultation to education staff at Murdoch Center.

6. Developing programs relating to human sexuality at Murdoch Center.

7. Teaching a core course to cottage attendants from Murdoch Center who are enrolled in the Durham Technical Institute.

8. Conducting inservice workshops at two state-operated residential facilities—Murdoch Center and Western Carolina Center.

9. Consultation to private residential facilities.

10. Studies of socio-cultural deprivation.

11. Participation in the State Developmental Disabilities Council.

12. Research in and consultation on self-inflicted injuries in certain types of residents in state facilities.

The Kansas University-Affiliated Facility

The Kansas University-Affiliated Facility incorporates three units located at Lawrence, Kansas City, and Parsons State Hospital and Training Center. This facility again combines the resources of a UAF and a MRRC. While the emphasis is on interdisciplinary training and research, programs of particular interest which provide direct impact on residential facilities are:

1. Development of behavior modification techniques and the evaluation of these techniques on residents; first in the institutional setting and then in the community (Mimosa Project).

2. Studies on residential environments and their effects.

3. Development of prototype living arrangements (Achievement Place—a residential facility for delinquent young people, some of whom are functionally retarded).

4. A preschool unit for normal and developmentally disabled children for intensive language training.

5. Technical assistance programs for local, state, and regional agencies.

6. Parent consultation and training programs.

7. Design and dissemination of films and workbooks.

8. Computer programming on documentation and evaluation of programs for the developmentally disabled.

The Center for Child Development at Georgetown University, Washington, D.C.

The Center for Child Development at Georgetown University[31] has a three-fold program of interdisciplinary professional training provided by faculty from 12 disciplines and 6 universities, inpatient pediatric care and outpatient services. Programs relating specifically to residential care:

1. Providing, by contract, medical services to the Maryland Great Oaks Center, a state residential facility.

2. Conducting a two-year program for training of "developmentalists" designed for training of personnel in the field of developmental disabilities by community colleges.

3. Conducting, in cooperation with the UAFs at the John Fitzgerald Kennedy Institute in Baltimore, Temple University in Philadelphia, the research and training centers at George Washington University in Washington, and the University of West Virginia, training programs for six Developmental Disabilities Councils in Delaware, the District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia.

4. Consulting with the University of West Virginia's R & T Center on a deinstitutionalization project in Morgantown, West Virginia.

5. Developing a "Life Skills for the Developmentally Disabled" project at Forest Haven, Laurel, Maryland.

6. Working with Clinch Valley College in Virginia, through the Virginia Developmental Disabilities Council on a continuing education basis to train students, agency staff, and volunteers to work with the developmentally disabled in a variety of settings.

The Rose Fitzgerald Kennedy Center, Yeshiva University, Bronx, New York

The Rose Fitzgerald Kennedy Center, Yeshiva University,[32] incorporates a UAF and a MRRC. This facility had its origins in 20 years of community service in child evaluation and rehabilitation in New York City. Among its affiliations are the Bronx Municipal Hospital and the Abraham Jacobi Hospital. It provides a full range of interdisciplinary training and research. Programs of note are:

1. Study of problems developing in the community programs in the State of New York.

2. A deinstitutionalization project.

3. Intensive short-term inpatient treatment programs.

4. Community services teams which stress crisis care in the community, liaison with other agencies, relevant treatment plans for the most economically depressed area of New York City with a predominantly minority population.

5. Training programs for all New York City Family Court Judges, Bronx Legislators, Bronx Social Welfare Agency leaders, Bronx Board of Education teachers of the mentally retarded, day care centers, head start programs, child health stations.

6. Training for parents' and consumer groups including the Willowbrook Benevolent Society.

7. Foster care programs.

8. Training for the adult developmentally disabled in self-care skills.

9. Operation of an adolescent psychotherapeutic unit.

10. Operation of transitional education and treatment center for severely handicapped ambulatory individuals to prepare them to enter community programs.

11. Model Rehabilitation Unit at Willowbrook Developmental Center focusing on adaptive behaviors of adults being prepared for resettlement.

The C. Louis Meyer Children's Rehabilitation Institute of The University of Nebraska Medical Center, Omaha, Nebraska

The C. Louis Meyer Children's Rehabilitation Institute[33] provides interdisciplinary training for professional and direct care personnel and specialized developmental services for children and youth with handicapping conditions. It functions as a state resource center for technical assistance to residential facilities and community programs serving the handicapped person. Outstanding programs are:

1. Preparation of extensive literature in the field of deinstitutionalization of severely and profoundly retarded and multiply handicapped people in community and institutional settings.

2. Demonstration programs in early, intensive, interdisciplinary approaches in prevention or ameliorating handicapping conditions.

3. Extensive work with programs of deinstitutionalization in the State of Nebraska.

A National Cooperative Effort

The UAFs at Harvard, the Georgia Retardation Center, the University of Kansas, the University of Washington, and Ohio State University were requested by Tulane University to help develop a curriculum and course outline for training evaluators of intermediate care facilities for the mentally retarded in the use of new standards and guidelines developed by HEW for these facilities. (It should be noted that this includes state residential facilities, group homes, nursing homes, and any 24-hour care facility for the mentally retarded receiving federal medicaid funds (Title XIX).) After the development of the curriculum, a five-day training course was held at each of the participating UAFs and approximately 150 evaluators were trained in the nature of mental retardation, development of individual habilitation plans, behavior management (physical-chemical-psychological), advocacy programs, development of human rights assurance committees, civil rights, recognition of appropriate and inappropriate living environments, concepts of the least restrictive alternatives to living in the natural home, and diagnosis of mental retardation. The potential impact of such a training program is immeasurable, and each residential facility, in order to continue to receive Title XIX funds, must comply with these newly developed guidelines by March 1977.

Elaboration on Two Models

Two UAFs are discussed here in some detail to illustrate the variety and volume of programs, both within their physical boundaries and outside, by participation in or operation of programs in the surrounding community. These two models are not superior in quality or quantity of programs. They are representative in most respects of the University-affiliated facilities.

The John F. Kennedy Institute for the Habilitation of the Mentally and Physically Handicapped Child

This facility is in the Johns Hopkins Hospital Complex in Baltimore, Maryland and is licensed as a Special Pediatric Hospital. Its considerable resources are enhanced by those of the Johns Hopkins medical institutions and are used for service and training by a wide variety of colleges and universities from a broad geographic area. The service area has no geographic restrictions. Retarded individuals, the majority aged 0 to 20, came from 22 states and 16 foreign countries during the period July 1, 1973–June 30, 1974, referred by a variety of individuals and agencies. The total number of "patient encounters" during this year was 40,419. A total of 1,943 "new patients" received services.

Statistical description of population served, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

	New in-patients	New out-patients	Total new patients
RESIDENCE			
State of Maryland:			
Baltimore City	54	942	996
Allegany County	3	3	6
Anne Arundel County	15	129	144
Baltimore County	26	301	327
Calvert County	0	5	5
Caroline County	3	1	4
Carroll County	5	11	16
Cecil County	9	17	26
Charles County	3	8	11
Dorchester County	2	2	4
Frederick County	1	6	7
Garrett County	0	1	1
Harford County	13	46	59
Howard County	0	26	26
Kent County	2	2	4
Montgomery County	9	32	41
Prince George's County	7	24	31
Queen Anne's County	6	1	7
St. Mary's County	4	6	10
Somerset County	2	2	4
Talbot County	4	4	8
Washington County	2	9	11
Wicomico County	14	14	28
Worchester County	9	3	12
Subtotal	193	1,595	1,788
Other States:			
Alabama	0	2	2
California	0	1	1
Connecticut	0	3	3
Delaware	1	5	6
District of Columbia	2	2	4
Florida	3	0	3
Georgia	0	2	2
Illinois	2	2	4
Kentucky	0	1	1
Louisiana	0	1	1
Massachusetts	0	1	1
Michigan	0	1	1
New Jersey	1	4	5
New York	5	5	10
North Carolina	0	3	3
Ohio	0	2	2
Pennsylvania	14	28	42
Rhode Island	0	1	1
South Carolina	1	0	1
Virginia	8	17	25
West Virginia	8	8	16
Subtotal	45	89	134
Other countries:			
Argentina	1	1	2
Bangladesh	0	1	1
Canada	0	1	1
Colombia	1	0	1
Costa Rica	0	1	1
Ethiopia	0	1	1
Greece	0	1	1
Honduras	0	1	1
Italy	0	1	1
Jamaica	1	0	1
Lebanon	1	0	1
Peru	2	0	2
Puerto Rico	0	1	1
Venezuela	2	2	4
Virgin Islands	0	1	1
Zambia	0	1	1
Subtotal	8	13	21
Total	246	1,697	1,943
REFERRAL SOURCES			
Private physicians	26	221	247
Public health	35	101	136
Crippled children's services	2	5	7
Mental health	3	10	13
Hospitals	133	1,088	1,141
Welfare agencies	5	25	30
Schools	6	160	166
Other community agencies	11	28	39

Statistical description of population served, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Continued

	New in-patients	New out-patients	Total new patients
Other sources (family, friends)	25	139	164
Total	246	1,697	1,943
AGES			
Less than 1 yr	8	55	63
1 to 2 yrs	60	285	345
3 to 4 yrs	63	265	328
5 to 6 yrs	22	236	258
7 to 8 yrs	14	216	230
9 to 10 yrs	16	204	220
11 to 12 yrs	20	145	165
13 to 14 yrs	10	112	122
15 to 16 yrs	12	94	106
17 to 19 yrs	17	59	76
20 yrs and older	4	26	30
Total	246	1,697	1,943

Patient encounters, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

Discipline	Total patients	In-patients	Out-patients
Hearing and speech:			
ECCC group	717	55	662
Evaluation	1,175	428	747
Individual	891	595	296
Parent training/counseling	29	23	6
Subtotal	2,812	1,101	1,711
Nursing service:			
Clinical nurse specialist	575	24	551
Public health nurse:			
Individual	316	87	229
Home visits	113	2	111
Other	386	48	338
Subtotal	1,390	161	1,229
Occupational therapy:			
Evaluation	609	426	183
Group	716	479	237
Individual	4,901	4,591	310
Other	377	312	65
Subtotal	6,603	5,808	795
Pediatric dentistry:			
Evaluation	652	210	442
Individual	528	72	456
Parent training/counseling	72	23	49
Subtotal	1,252	305	947
Pediatric psychiatry:			
Individual	409	58	351
Parent training/counseling	53	5	48
Subtotal	462	63	399

Patient encounters, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Continued

Discipline	Total patients	In-patients	Out-patients
Physical therapy:			
Evaluation	332	224	108
Group	672	643	29
Individual	9,114	8,511	603
Other	13	8	5
Subtotal	10,131	9,386	745
Psychological testing and evaluation:			
Individual	1,409	338	1,071
Parent counseling	36	7	29
Other	22	6	16
Subtotal	1,467	351	1,116
Psychology:			
Testing	206	83	123
Group	2,517	1,384	1,133
Individual	2,369	1,711	658
Parent training/counseling	333	113	220
Subtotal	5,425	3,291	2,134
Social service:			
Group	248	61	187
Home visits	122	5	117
Individual	2,415	719	1,696
Other	1,747	547	1,200
Subtotal	4,532	1,332	3,200
Special education:			
Evaluation	301	70	231
Group	849	405	444
Individual	481	421	60
Other	69	30	39
Subtotal	1,700	926	774
Clinics:			
Birth defects center	250	0	250
Cerebral palsy	127	0	127
Child development and special pediatrics	996	0	996
Diagnostic and evaluation center	858	0	858
Electroencephalography	526	230	296
Lead paint poisoning prevention	710	57	653
Nutrition service	71	59	12
Ophthalmology	81	0	81
Orthopedic	253	0	253
Seizure	853	0	853
Subtotal	4,725	346	4,379
Total	40,499	23,070	17,429

Average encounters per month

Inpatients	1,922.5
Outpatients	1,452.4
Total patients	3,374.9

Average encounters per day (250 work days)

Inpatients	92.2
Outpatients	69.7
Total patients	161.9

Statistical description of outpatients by number of visits[1], *the John F. Kennedy Institute, July 1, 1973–June 30, 1974*

	All patients		New patients		Old patients	
	Patients	Visits	Patients	Visits	Patients	Visits
1 visit	1,070	1,070	702	702	368	368
2 visits	651	1,302	431	862	220	440
3 visits	353	1,059	220	660	133	399
4 visits	204	816	134	536	70	280
5 to 9 visits	432	2,782	257	1,646	175	1,136
10 or more visits	222	5,406	108	1,780	124	3,626
Total	2,942	12,435	[2] 1,852	6,186	1,090	6,249

[1] For the purpose of this report, a visit is defined as an appearance by the patient or his family at the Kennedy Institute for 1 or more services, or a visit to the patient's home by a member of the staff. Only 1 visit is counted for a single day, regardless of the number of services provided.

[2] Total includes 155 new inpatients who were also seen as outpatients, but are not included in the "statistical description of population served" as new outpatients, to prevent counting them twice.

NOTE.—Average number of visits per patient: New patients, 3.34; old patients, 5.73; all patients, 4.22.

Summary of inpatient statistical data compared to 3 previous years

	Fiscal year 1974	Fiscal year 1973	Fiscal year 1972	Fiscal year 1971
Inpatient admissions	321	252	224	258
Inpatient discharges	312	257	234	253
Days of care rendered to inpatients	8,328	8,341	10,510	10,726
Average daily census	22.83	22.85	28.74	29.11
Average length of stay (days)	26.19	31.86	46.85	44.46
Average bed occupancy rate (based on 40 bed capacity) (percent)	57.06	57.13	71.81	72.85

NOTE.—When evaluating the above statistics, consideration should be given to the number of patient days which are not countable due to the placement of most patients on therapeutic leave of absence with their families during weekends and holidays, even though their beds must be held in reserve during these periods of absence. As a result, the average daily census, length of stay, and bed occupancy rate are lower by approximately 25 pct.

Consultations[1], the John F. Kennedy Institute, July 1, 1973–June 30, 1974

Discipline	Number of consultations	Number of time units[2]
Hearing and speech	5	14
Lead paint poisoning prev. cl	785	822
Occupational therapy	2	8
Pediatric dentistry	2	4
Physical therapy	12	48
Psychiatry	16	64
Psychological testing	175	814
Psychology	1	8
Public health nursing	73	127
Social services	52	119
Special education	70	255
Total	1,193	2,283

[1] For the purpose of this report, a consultation is a person who receives services or technical assistance as a part of the JFKI program but is not registered as an institute case. These services are normally requested by agencies such as schools, courts, probation officers, police, social and welfare agencies, health agencies, and private physicians or dentists.

[2] One time unit is the equivalent of 15 min.

Number of trainees by affiliation, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

Affiliation:	Number of trainees
American University, Washington, D.C.	4
Baltimore City Department of Social Services, Baltimore, Md	180
Bryman Medix School	3
Catholic University of America, Washington, D.C.	4
Catonsville Community College, Catonsville, Md.	98
Church Home and Hospital, Baltimore, Md	18
Columbia University, New York, N.Y	4
Community College of Baltimore, Baltimore, Md.	50
Coppin State College, Baltimore, Md	31
Dundalk Community College, Dundalk, Md	9
Essex Community College, Essex, Md	7
George Washington University, Washington, D.C.	2
Gettysburg College, Gettysburg, Pa	1
Goucher College, Baltimore, Md	3
Ithaca College, Ithaca, N.Y	4
Johns Hopkins Hospital:	
Child Life Department	1
Children's Medical and Surgical Center	1
Department of Child Psychiatry	2
Department of Pediatrics	18
Johns Hopkins University:	
Department of Special Education	39
School of Hygiene and Public Health	5
School of Medicine	47
Johnston School of Practical Nursing, Baltimore, Md	2
Kennedy Institute Fellows	11
Loyola College, Baltimore, Md	14
Maryland General Hospital, School of Nursing, Baltimore, Md	36
Maryland School for the Blind, Baltimore, Md	1
Morgan State College, Baltimore, Md	1
Ohio State University, Columbus, Ohio	2
Pennsylvania State University, University Park, Pa	2
St. Agnes Hospital, Department of Pediatrics, Baltimore, Md	1
St. Francis School for Special Education, Baltimore, Md	1
St. Mary's College of Maryland, St. Mary's City, Md	2
St. Timothy's School, Stevenson, Md	1
Towson State College, Towson, Md	9
Tufts University, Medford, Mass	1
Tuskegee Institute, Baltimore, Md	39
Union Memorial Hospital: Baltimore, Maryland	24
University of Maryland:	
Department of Psychology	5
Department of Sociology	7
Law School	1
School of Dentistry	32
School of Medicine	28
School of Nursing	19
School of Social Work	60
University of North Carolina, Chapel Hill, N.C	1
University of St. Louis, St. Louis, Mo	1
U.S. Navy	1
Utica College of Syracuse University, Utica, N.Y	2
Virginia Commonwealth University, Richmond, Va	2
Walter Reed General Hospital, Washington, D.C.	3
Washington Hospital Center, School of Nursing, Washington, D.C	11
Western Maryland College, Westminster, Md	2
Wittenburg University, Springfield, Ohio	1
No Affiliation	1
Total	855

Trainee status by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

	Hours of training						Total
	8–40[1]	41–160	161–500	501–1,000	1,001–2,000	2,000–up	
Post-M.D. fellow:							
Clinical services	0	0	0	0	2	5	7
Genetics laboratory	1	0	0	0	0	0	1
Pediatric psychiatry	0	0	2	0	0	0	2
Post-D.D.S. fellow: Pediatric dentistry	2	3	0	2	0	0	7
Post-Ph. D. fellow:							
Genetics laboratory	0	1	0	0	0	0	1
Psychological testing	0	0	1	0	0	0	1
Psychology	0	0	2	0	2	0	4
Intern or resident:							
Clinical services	1	0	18	0	0	0	19
Genetics laboratory	0	1	0	0	0	0	1
M.D. degree candidate:							
Clinical services	0	26	13	2	0	0	41
Genetics laboratory	0	1	1	0	0	0	2
Special education	0	2	0	0	0	0	2
D.D.S. degree candidate: Pediatric dentistry	0	1	0	0	0	0	1
Ph. D. degree candidate:							
Administration	0	1	0	0	0	0	1
Hearing and speech	0	3	0	0	0	0	3
Psychology	1	4	1	5	0	0	11
Social service	0	0	0	1	0	0	1
Special education	0	0	1	0	2	0	3
Post-master's nondegree:							
Occupational therapy	0	0	1	0	0	0	1
Psychological testing	0	1	[illegible]	0	0	0	1
Social service	0	0	3	0	0	0	3
Special education	6	0	1	0	0	0	7
Master's degree candidate:							
Administration	0	1	0	0	1	0	2
Child development	1	0	0	0	0	0	1
Hearing and speech	0	0	3	3	0	0	6
Nursing service	0	5	0	0	0	0	5
Occupational therapy	0	1	0	0	0	0	1
Psychology	1	1	0	0	0	0	2
Social service	40	0	6	14	0	0	60
Special education	32	5	12	0	0	0	49
Postbaccalaureate nondegree:							
Genetics laboratory	1	0	0	0	0	0	1
Occupational therapy	0	0	5	0	0	0	5
Physical therapy	1	0	0	0	0	0	1
Psychology	0	1	0	0	0	0	1
Social service	180	0	1	0	0	0	181
Special education	9	2	0	0	0	0	11
Baccalaureate degree candidate:							
Child development	3	1	3	0	0	0	7
Genetics laboratory	0	0	3	0	0	0	3
Hearing and speech	0	3	0	0	0	0	3
Nursing service	34	19	0	0	0	0	53
Occupational therapy	0	0	3	0	0	0	3
Pediatric dentistry	25	0	0	0	0	0	25
Physical therapy	18	4	9	0	0	0	31
Baccalaureate degree candidate:							
Psychology	2	2	4	0	0	0	8
Public relations	0	0	2	0	0	0	2
Social service	0	3	5	1	0	0	9
Special education	9	0	1	0	0	0	10
Associate of arts degree candidate:							
Child development	9	5	0	0	0	0	14
New careers	0	1	2	7	8	0	18
Nursing service	98	0	0	0	0	0	98
Occupational therapy	1	0	0	0	0	0	1
Pediatric density	4	0	0	0	0	0	4
Physical therapy	12	0	0	0	0	0	12
Special education	4	4	3	0	0	0	11

Trainee status by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Continued

	Hours of training						Total
	8–40 [1]	41–160	161–500	501–1,000	1,001–2,000	2,000–up	
Certificate or diploma candidate:							
Nursing service	91	0	0	0	0	0	91
Pediatric dentistry	3	2	0	0	0	0	5
Miscellaneous: Special education	0	1	0	0	0	0	1
Total	589	105	106	35	15	5	855

[1] In addition to the training depicted here, there were numerous orientation sessions lasting less than 8 hrs.

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

AFFILIATION	Number of trainees
Administration:	
George Washington University	2
University of Maryland Law School	1
Subtotal	
Child development:	
Community College of Baltimore	12
Essex Community College	2
Pennsylvania State University	2
Towson State College	2
University of Maryland, School of Medicine	2
University of North Carolina	1
Western Maryland College	1
Subtotal	22
Clinical services:	
Johns Hopkins Hospital, Department of Pediatrics	18
Johns Hopkins University, School of Medicine	41
Kennedy Institute Fellows (MCH grant)	7
St. Agnes Hospital	1
Subtotal	67
Genetics laboratory:	
Johns Hopkins Hospital, Children's Medical and Surgical Center	1
Johns Hopkins University, School of Hygiene and Public Health	2
Johns Hopkins University, School of Medicine	2
Tufts University	1
U.S. Navy	1
Western Maryland College	1
Whittenbrug University	1
Subtotal	9
Hearing and speech:	
Johns Hopkins University, School of Hygiene and Public Health	3
Loyola College	9
Subtotal	12
New careers: Community College of Baltimore, concentrated employment program	18
Subtotal	18
Nursing service:	
Catonsville Community College	98
Church Home and Hospital	18
Johnston School of Practical Nursing	2

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Con.

	Number of trainees
Maryland General Hospital, School of Nursing	36
Tuskegee Institute	39
Union Memorial Hospital	24
University of Maryland, School of Nursing	19
Washington Hospital Center, School of Nursing	11
Subtotal	247
Occupational therapy:	
Columbia University	4
Community College of Baltimore	1
Ohio State University	2
Utica College of Syracuse University	2
Virginia Commonwealth University	2
Subtotal	11
Pediatric dentistry:	
Bryman Medix School	3
Community College of Baltimore	5
Essex Community College	2
University of Maryland, School of Dentistry	32
Subtotal	42
Pediatric psychiatry: Johns Hopkins Hospital, Department of Child Psychiatry	2
Physical therapy:	
Community College of Baltimore	12
Ithaca College	4
Maryland School for the Blind	1
University of Maryland, School of Medicine	26
University of St. Louis	1
Subtotal	44
Psychological testing and evaluation:	
Johns Hopkins University, School of Medicine	1
St. Francis School for Special Education	1
Subtotal	2
Psychology:	
American University	3
Catholic University	2
Gettysburg College	1
Goucher College	3
Johns Hopkins Hospital, Child Life Department	1
Johns Hopkins University, School of Medicine	1
Kennedy Institute Fellows	4
Loyola College	2
Towson State College	4

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Con.

	Number of trainees
Psychology – Continued	
University of Maryland, Department of Psychology	5
Subtotal	26
Public relations:	
American University	1
Towson State College	1
Subtotal	2
Social service:	
Baltimore City Department of Social Services	180
Catholic University of America	2
Coppin State College	1
St. Mary's College of Maryland	1
University of Maryland, Baltimore County, Department of Sociology	7
University of Maryland, School of Social Work	60
Walter Reed General Hospital	3
Subtotal	254
Special education:	
Community College of Baltimore	2
Coppin State College	30
Dundalk Community College	9
Essex Community College	3
Johns Hopkins University, Department of Special Education	39
Johns Hopkins University, School of Medicine	2
Loyola College	3
Morgan State College	1
St. Mary's College of Maryland	1
St. Timothy's School	1
Towson State College	2
No affiliation	1
Subtotal	94
Total trainees	855

Over 850[34] trainees from 54 affiliating departments, colleges, and universities representing 16 categories of disciplines received training ranging from the certificate or diploma to post-doctoral level.

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

Affiliation	Number of trainees	
	Through Dec. 31, 1973	Projection through June 30, 1974
Administration:		
George Washington University	1	3
University of Maryland Law School	1	1
Subtotal	2	4
Child development:		
Community College of Baltimore	6	16
Essex Community College	2	3
George Washington University	0	1
Pennsylvania State University	2	2
Towson State College	2	2
University of Maryland, School of Medicine	1	1
University of North Carolina	1	1
Western Maryland College	0	1
Subtotal	14	27
Clinical services:		
Johns Hopkins Hospital, Depart- of Pediatrics	9	18
Johns Hopkins University, School of Medicine	20	57
Kennedy Institute Fellows (MCH grant)	7	7
St. Agnes Hospital	1	2
Subtotal	37	84
Genetics laboratory:		
Johns Hopkins Hospital, Children's Medical and Surgical Center	1	1
Johns Hopkins University, School of Hygiene and Public Health	1	2
Johns Hopkins University, School of Medicine	1	1
Tufts University	0	1
Western Maryland College	0	1
Subtotal	3	6
Hearing and speech:		
Johns Hopkins University, School of Hygiene and Public Health	2	3
Loyola College	6	9
University of Maryland, Department of Speech and Hearing Science	0	1
Subtotal	8	13
New careers: Community College of Baltimore, concentrated employment program	18	18
Nursing service:		
Catonsville Community College	0	70
Church Home and Hospital	12	26
Johnston School of Practical Nursing	0	20
Maryland General Hospital	10	30
Tuskegee Institute	20	38
University of Maryland	4	61
Washington Hospital Center	11	35
Subtotal	57	280
Occupational therapy:		
Columbia University	2	4
Community College of Baltimore	1	4

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Con.

Affiliation	Number of trainees	
	Through Dec. 31, 1973	Projection through June 30, 1974
Occupational therapy—Continued		
Ohio State University	0	2
Utica College of Syracuse University	1	2
Virginia Commonwealth University	1	2
Subtotal	5	14
Pediatric dentistry:		
Community College of Baltimore	0	27
Essex Community College	2	5
University of Maryland, School of Dentistry	2	10
Subtotal	4	42
Pediatric psychiatry: Johns Hopkins Hospital, Department of Child Psychiatry	1	2
Physical therapy:		
Community College of Baltimore	12	24
Ithaca College	2	5
Temple University	0	1
University of Maryland, School of Medicine	14	35
University of St. Louis	1	1
Subtotal	29	66
Psychological testing and evaluation:		
Johns Hopkins Hospital, Department of Pediatrics	1	1
St. Francis School for Special Education	1	1
Subtotal	2	2
Psychology:		
American University	3	3
Catholic University	2	2
Gettysburg College	0	1
Goucher College	2	3
Johns Hopkins Hospital, Child Life Department	1	1
Johns Hopkins University	1	1
Kennedy Institute Fellows	4	4
Loyola College	0	2
Towson State College	4	4
University of Maryland, Department of Psychology	3	3
Subtotal	20	24
Public relations: American University	1	1
Social service:		
Baltimore City Department of Social Services	120	180
Catholic University	2	2
St. Mary's College	1	1
University of Maryland, Baltimore Campus, Department of Sociology	3	5

Training affiliations by discipline, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Con.

Affiliation	Number of trainees	
	Through Dec. 31, 1973	Projection through June 30, 1974
University of Maryland, School of Social Work	57	100
Walter Reed General Hospital	0	3
Subtotal	183	291
Special education:		
Community College of Baltimore	1	1
Coppin State College	13	23
Dundalk Community College	9	15
Essex Community College	2	5
Johns Hopkins University	23	34
Loyola College	3	5
Morgan State College	1	1
St. Mary's College	1	1
St. Timothy's High School	0	1
Towson State College	1	1
Miscellaneous	1	1
Subtotal	55	88
Total trainees	439	962

Number of trainees by affiliation, the John F. Kennedy Institute, July 1, 1973–June 30, 1974

Affiliation	Number of trainees	
	Through Dec. 31, 1973	Projection through June 30, 1974
American University, Washington, D.C	4	4
Baltimore City Department of Social Services, Baltimore, Md	120	180
Catholic University, Washington, D.C	4	4
Catonsville Community College, Catonsville, Md	0	70
Church Home and Hospital, Baltimore, Md	12	26
Columbia University, New York, N.Y	2	4
Community College of Baltimore, Baltimore, Md	38	90
Coppin State College, Baltimore, Md	13	23
Dundalk Community College, Dundalk, Md	9	15
Essex Community College, Essex, Md	6	13
George Washington University, Washington, D.C	1	4
Gettysburg College, Gettysburg, Pa	0	1
Goucher College, Baltimore, Md	2	3
Ithaca College, Ithaca, N.Y	2	5
Johns Hopkins Hospital:		
Child Life Department	1	1
Children's Medical and Surgical Center	1	1
Department of Child Psychiatry	1	2
Department of Pediatrics	10	19

Number of trainees by affiliation, the John F. Kennedy Institute, July 1, 1973–June 30, 1974—Continued

Affiliation	Number of trainees	
	Through Dec. 31, 1973	Projection through June 30, 1974
Johns Hopkins University:		
Department of Special Education	23	34
School of Hygiene and Public Health	4	6
School of Medicine	21	58
Johnston School of Practical Nursing, Baltimore, Md.	0	20
Kennedy Institute Fellows	11	11
Loyola College, Baltimore, Md.	9	16
Maryland General Hospital, School of Nursing, Baltimore, Md.	10	30
Morgan State College, Baltimore, Md.	1	1
Ohio State University, Columbus, Ohio	0	2
Pennsylvania State University, University Park, Pa.	2	2
St. Agnes Hospital, Department of Pediatrics, Baltimore, Md.	1	2
St. Francis School for Special Education, Baltimore, Md.	1	1
St. Mary's College, St. Mary's City, Md.	2	2
St. Timothy's High School, Baltimore, Md.	0	1
Temple University, Philadelphia, Pa.	0	1
Towson State College, Towson, Md.	7	7
Tufts University, Medford, Mass.	0	1
Tuskegee Institute, Baltimore, Md.	20	38
University of Maryland:		
Department of Psychology	3	3
Department of Sociology	3	5
Department of Speech and Hearing Science	0	1
Law School	1	1
School of Dentistry	2	10
School of Medicine	15	36
School of Nursing	4	61
School of Social Work	57	100
University of North Carolina, Chapel Hill, N.C.	1	1
University of St. Louis, St. Louis, Mo.	1	1
Utica College of Syracuse University, Utica, N.Y.	1	2
Virginia Commonwealth University, Richmond, Va.	1	2
Walter Reed General Hospital, Washington, D.C.	0	3
Washington Hospital Center, School of Nursing, Washington, D.C.	11	35
Western Maryland College, Westminster, Md.	0	2
Miscellaneous	1	1
Total trainees	439	962

The community education program includes an ongoing series of lectures, seminars, and symposia, held throughout the year. From September 1973–May 1974, 32 community education programs were given.

The John F. Kennedy Institute
September 1973–May 1974

September—Pediatric Dentistry:

September 7, 1973	*Clinical Management of the Handicapped Child in Pediatric Dentistry*, by Dr. Lawrence A. Fox, Director, Pediatric Dentistry Division, The John F. Kennedy Institute.
September 14, 1973	*Thumbsucking—Does it Harm Facial Growth?*, by Dr. David Owen, Assistant Professor, University of Maryland School of Dentistry, Department of Pedodontics.
September 21, 1973	*Nutritional Aspects of Dental Health*, by Dr. David Paige, Assistant Professor, Maternal and Child Health, The Johns Hopkins University School of Hygiene and Public Health.
September 28, 1973	*Dental Genetics in Handicapping Conditions*, by Dr. Steven Levin, Fellow in Medicine, The Johns Hopkins University and Hospital.

October—Psychiatry:

October 12, 1973	*Adolescence and the Handicapped*, by Dr. Ghislane Godenne, Director of Counseling and Psychiatric Service, The Johns Hopkins University.
October 19, 1973	*Adolescence, Sexuality and the Mentally Retarded*, by Dr. Warren Johnson, Director, Children's Health and Developmental Clinic, University of Maryland, College Park.
October 26, 1973	*Developmental Disabilities: From a Personal Viewpoint*, by Mr. Phil Monetti, a handicapped parent.

November—Peripheral Social Issues Affecting the Handicapped Child:

November 2, 1973	*Conscience is a Dirty Word*, by Dr. Gene Gordon, Child Psychoanalyst at the Baltimore-D.C. Analytic Institute and Associate Psychiatrist, Children's Hospital in Washington, D.C.
November 9, 1973	*Social Attitudes Towards the Handicapped*, by Mr. Paul Marchand, Head of Legislative Affairs, National Association for Retarded Children.
November 16, 1973	*The Effects of Alcoholism on the Young Child*, by Mr. Donald G. Phelps, Director of the Division of Prevention, National Institute on Alcohol Abuse and Alcoholism, Washington, D.C.
November 30, 1973	*The Impaired Family in Drug Abuse*, by Dr. William Abramson, Director of the Community Drug Abuse Program, Sheppard Pratt Hospital.

December—No Lectures

January—Psychological Testing and Evaluation:

January 4, 1974	*Infant Tests and Other Predictors of Low I.Q. at Age Four*, by Dr. Sarah Broman, National Institute of Neurological Disease and Stroke (NINDS).
January 11, 1974	*Screening for Behavior and Learning Problems in the Early School Years*, by Dr. Leon A. Rosenberg, Associate Professor, Medical Psychology and Pediatrics, The Johns Hopkins University.
January 18, 1974	*Is Developmental Dysphasia a Defect of Perception, But Not Language?*, by Dr. Paul Tallal, Postgraduate Fellow, Department of Psychology, The Johns Hopkins University.
January 25, 1974	*Inhibitory Control of Behavior: Its Measurement and Neuroanatomical Bases*, by Dr. David Olton, Assistant Professor, Psychology, The Johns Hopkins University.

February—Social Service:

February 1, 1974	*The Mentally Retarded Juvenile Offender*, by Mr. Paul Smith, Esq., Judge, Baltimore City Juvenile Court.
February 8, 1974	*Foster Care Programs for the Developmentally Disabled Child*, by Ms. Judy Lieshman, Social Worker, Baltimore City Department of Social Services.
February 15, 1974	*Who Should be Institutionalized?*, by Dr. Wesley White, Director, Whitehaven Home and Hospital, Pennsylvania, and Dr. Marvin Malcotti, Director, Rosewood State Hospital.
February 22, 1974	*Health Care, Education and Recreation for Handicapped Children*—A Panel Discussion, by Ms. Rebecca Polen, Clinical Social Worker, Social Service Division, The John F. Kennedy Institute.

March—Special Education:

March 1, 1974	*Work-Study Program for the Physically Handicapped*, by Mrs. Mary Lupien, Principal, Battle Monument School.
March 8, 1974	*Educational Needs of Trainable Adults*, by Ms. Sherrie Smithson, Assistant Director of Activity Center, Baltimore Association for Retarded Citizens.
March 15, 1974	*Education for Adult Aphasic Patients*, by Mr. Roger Walters, Speech Pathologist, Good Samaritan Hospital.
March 20, 1974	*Kennedy Special Education School*, by Dr. John T. Guthrie, Director, Special Education Division, and Mr. Ronald I. Caplan, Principal, the Kennedy School, The John F. Kennedy Institute.
March 22, 1974	*Case Study of a Dyslexic Adult*, by Dr. John T. Guthrie, Director, Special Education Division, The John F. Kennedy Institute.

April—Developmental Disabilities:

April 5, 1974	*Mental Retardation.*
April 12, 1974	*Cerebral Palsy.*
April 19, 1974	*Epilepsy.*
April 26, 1974	*Autism.*

May—Informed Consent for Dependent Children:

May 3, 1974 *Children*, by Dr. Norman Fost, Associate Professor of Pediatrics, University of Wisconsin, and Mr. Charles Lowe, Scientific Project Director, National Institute of Child and Human Development (NICHD).

May 10, 1974 *The Retarded*, by Dr. Robert E. Cooke, Vice Chancellor for Health Sciences, University of Wisconsin, and Ms. Joan Giles, Willowbrook State Hospital, New York.

May 17, 1974 *The Fetus*, by Dr. Andre Hellegers, Director, The Joseph and Rose Kennedy Institute, and Dr. Howard Jones, Professor of Gynecology and Obstetrics, The Johns Hopkins University.

May 24, 1974 *The Adolescent*, by Dr. Felix Heald, Professor of Pediatrics, Director, Division of Adolescence, University of Maryland, and Dr. Arthur Dyke, Professor of Population Ethics, Divinity School, Harvard University.

Projects and services of particular relevance are:

1. A five year study to follow approximately 200 mentally retarded individuals who have been transferred from a large institution to a smaller community-oriented facility closer to their homes. The purpose is to document the long-term effects of the "deinstitutionalization" phenomena, including changes in skills, functional and intellectual activity, sociability, and the influence upon the family and community.

2. Formulation of a curriculum for the education of the trainable and severely retarded child.

3. A screening program for Tay-Sachs disease.

4. A lead poisoning screening program.

5. Learning disability remediation research.

6. A double-blind study of certain pharmacologic agents for the control of movement disorders in children with cerebral palsy.

7. A biochemical study of certain lysozymal disorders in retarded children.

8. Investigation of speech mechanisms and auditory processing in retarded children.

9. Development of an information and referral service manned by volunteers.

10. Publication of a comprehensive manual of available services for the handicapped in the State of Maryland.

The basic philosophy here is that training and the improvement of services are interdependent. " . . . Improvement in residential services will coincide with well-trained professionals who provide diagnostic treatment, education, and other services which may effectively deal with a variety of conditions and problems encountered in the mentally retarded population."[35]

The Georgia Retardation Center

This facility is located on two sites—one in Atlanta, Georgia and one in Athens, Georgia. The Center (Atlanta and Athens) is owned and administered by the Georgia Department of Human Resources, but the programs of the Athens Unit represent a joint effort of the University of Georgia and the Georgia Department of Human Resources. The university-affiliated program is not separate and distinct, but rather woven throughout all the Center's programs. The Center's concerns are service, manpower development, research, and community education and technical assistance, all based together in a "unit system" structure. Services and community education and technical assistance are restricted geographically to the northern section of Georgia, which has a population of over 2 million. The one exception to this is dental service provided to any developmentally disabled individual within the state. Affiliations for the manpower development and research programs have no geographic limitations.

From July 1, 1973–June 30, 1974, the Center provided 169,096 days of residential programs (see Chart 1). The Atlanta facility operates seven days per week while the Athens facility operates five days per week. A total of 1,111 individuals received diagnostic and evaluation services, and 465 individuals received services one or more times on a nonresidential basis for a total of 2,341 visits (see Charts 2 & 3).

CHART 1

INPATIENT ADMISSIONS

FY 1973 - FY 1974

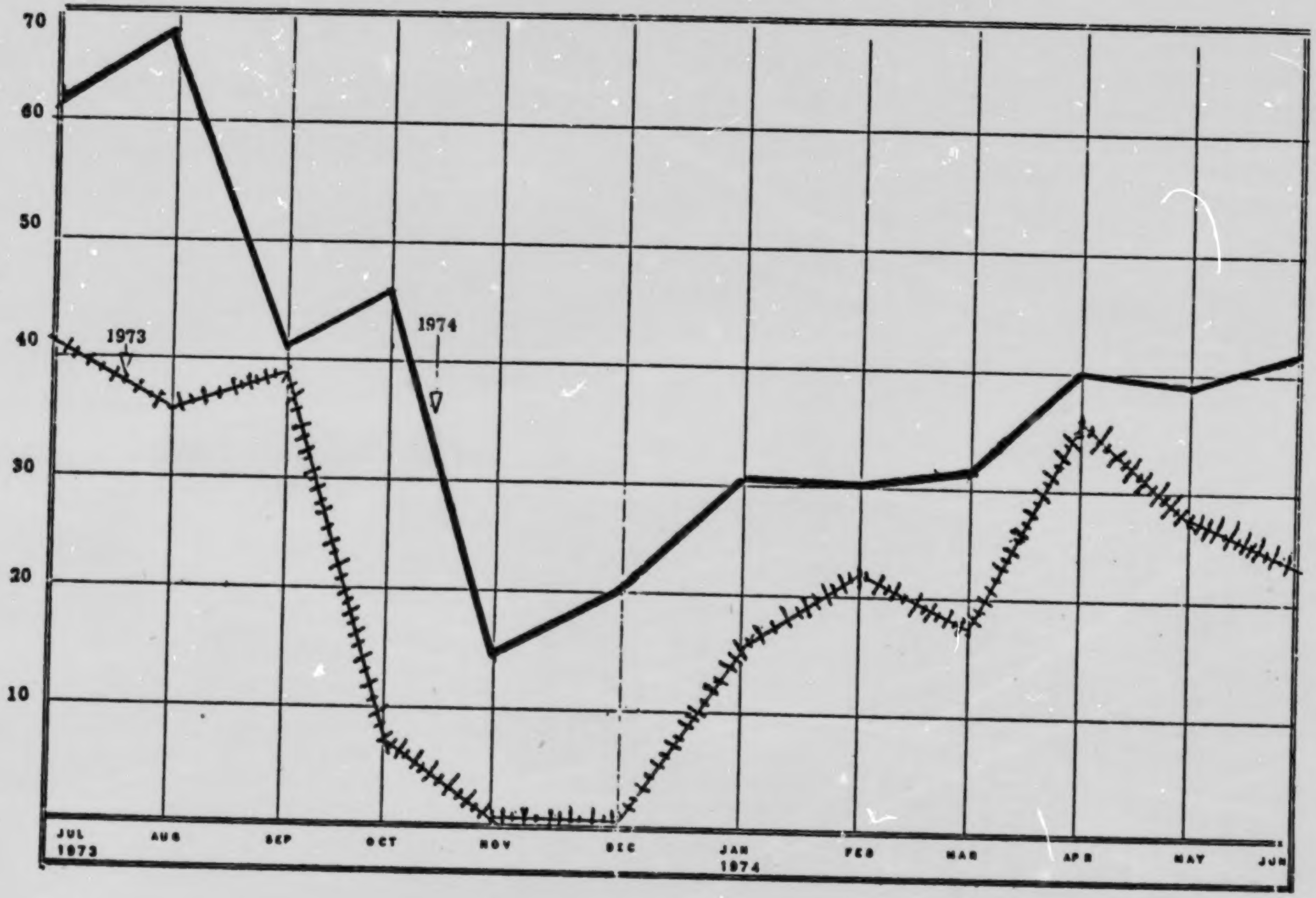


CHART 2

OUT PATIENT ADMISSIONS
July 1972 through June 1974

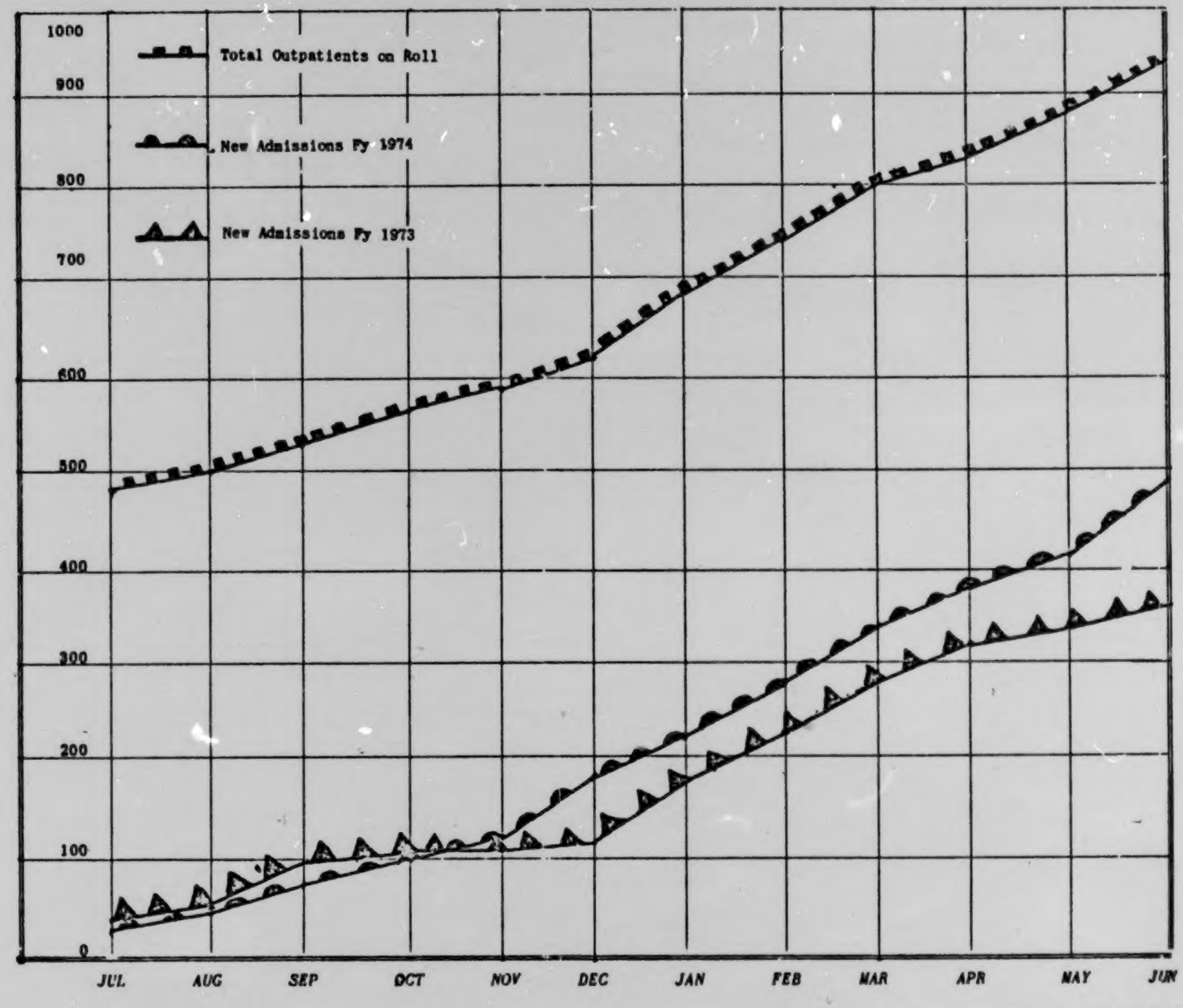
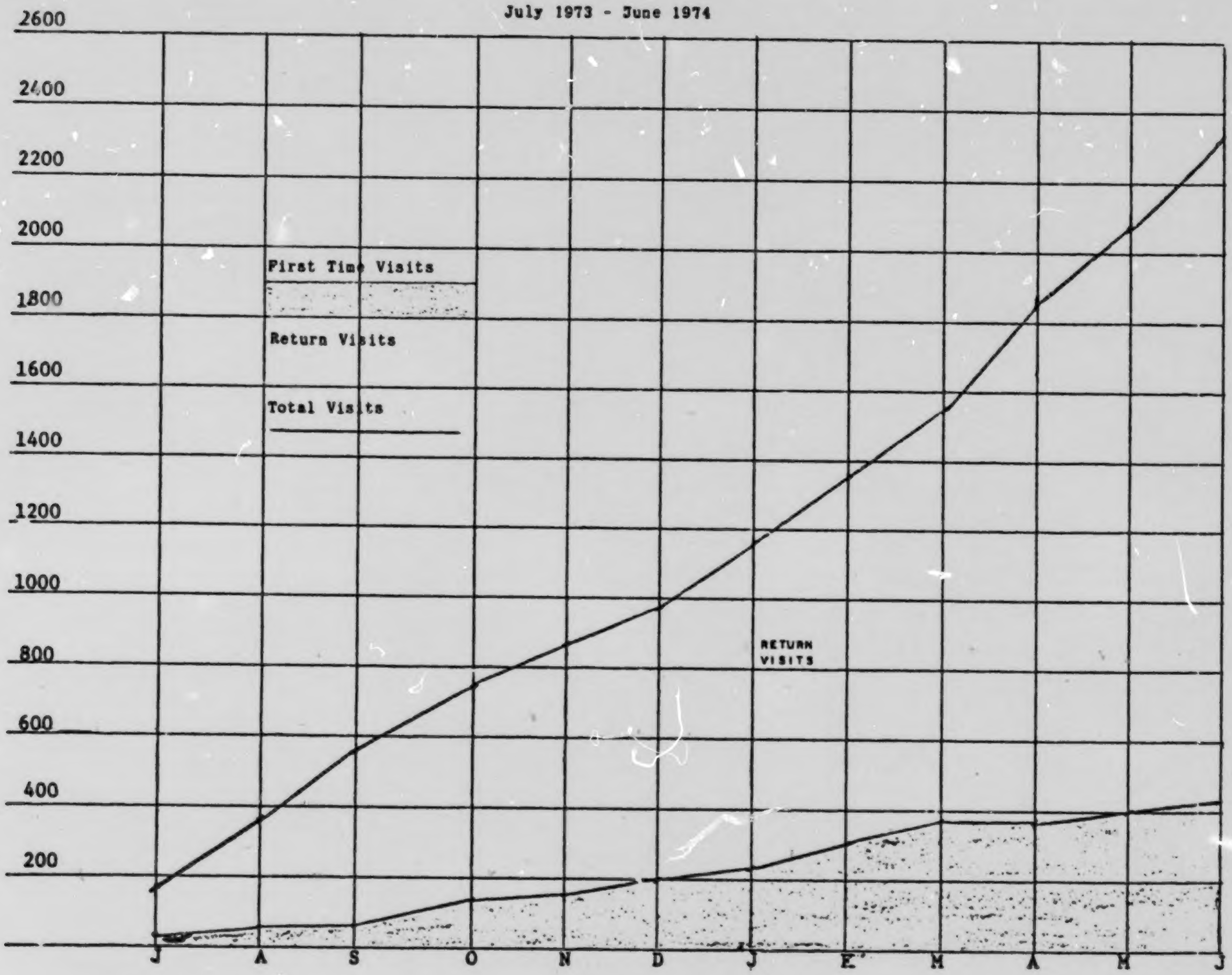


CHART 3

OUT PATIENT VISITS

July 1973 - June 1974



Inservice education, primarily for residential care employees,[36] provided 30,000 hours of course instruction in the following categories (see Chart 4):

1. Supervision and management—141 individuals.
2. Activities of daily living—616 individuals.
3. Leisure time activities—350 individuals.
4. Orientation to mental retardation—480 individuals.

There are 57 departments from 17 colleges and universities in the university-affiliated program representing 15 disciplines (see Charts 5, 6, 7). This program had 3,350 trainees during the year 1973–74, while 1,432 trainees were reported in the earlier "Mayeda" Report. The research programs represent both basic

CHART 4-

IN-SERVICE TRAINING

FY 1974, 1975, 1976

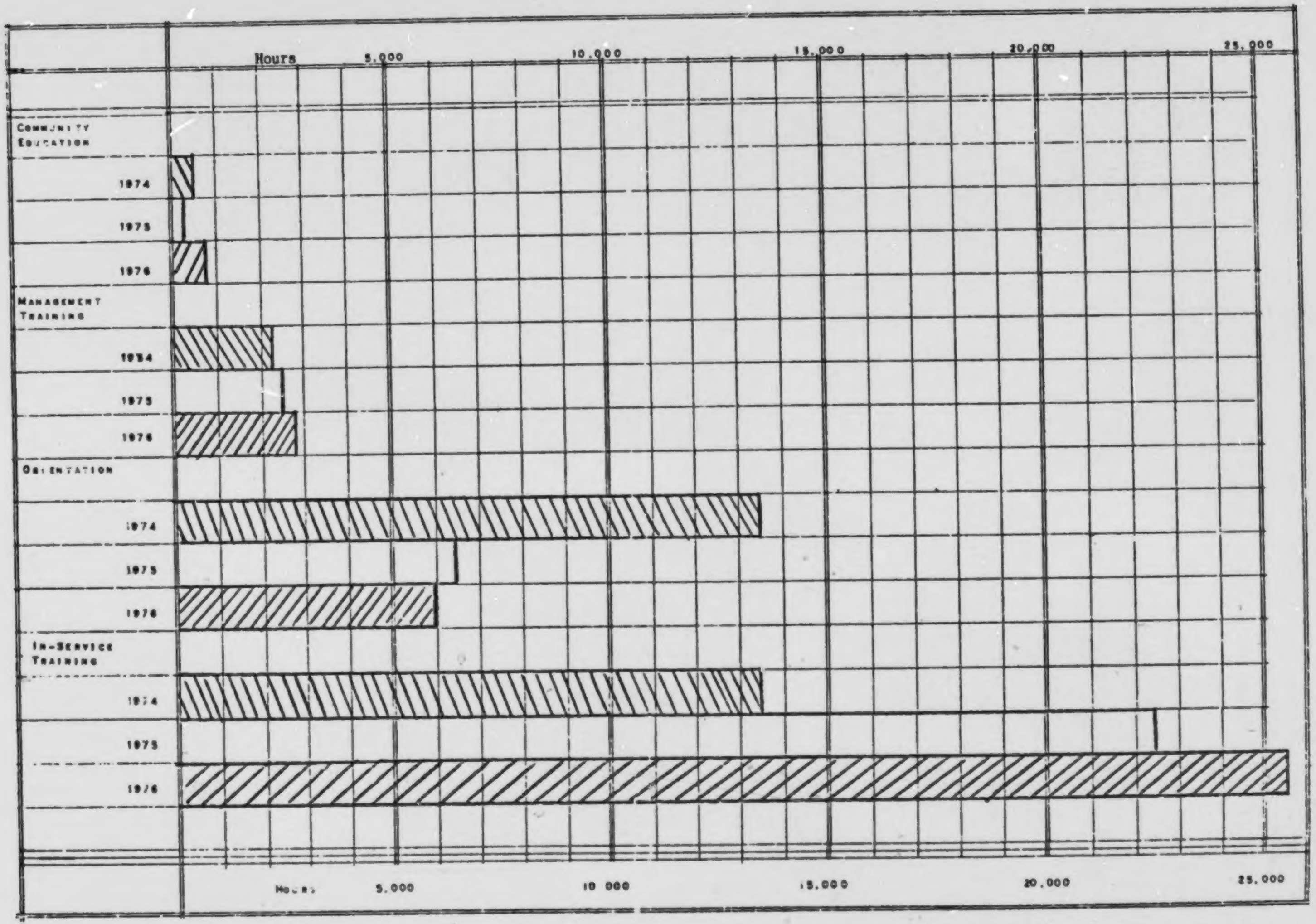


CHART 5

AFFILIATED TRAINING AGREEMENTS
COMPARISON OF PROJECTED/ACTUAL AGREEMENTS

UNIVERSITY	DEPARTMENT	AGREEMENTS PROJECTED 1965	CURRENT AGREEMENTS	AGREEMENTS PENDING
Medical College of Georgia	Dentistry			▤
	Dental Hyg.			▤
	Nursing			▤
	P.T.		▨	
	O.T.		▨	
	Pediatrics			▤
Mercer University	Southern School of Pharmacy		▨	
Crawford W. Long	Nursing		▨	
Alabama in Birmingham	P.T.		▨	
Duke	P.T.		▨	
Clayton Jr. College	Nursing		▨	
Oglethorpe	Education Sociology		▨	
Kennesaw	Recreation		▨	
Ga. Tech	Architecture Psychology			▤
I.T.C.	Religion	▨	▨	
Atlanta U.	Social Work Spec. Ed.	▨	▨	
Georgia State University	Nutrition		▨	
	Nursing		▨	
	Coun = Ed. Psy.		▨	
	M.H. Asst.		▨	
	P.T.		▨	
	Biology		▨	
	Clinical Music		▨	
	Psychology (Grad.)	▨	▨	
	Spec. Ed.	▨	▨	
Emory University	Sociology Dentistry Sp. & Hearing Religion Psychology Nursing O.T. P.T. Pediatrics Psychiatry Nutrition	▨	▨	
University of Georgia	Social Work Sociology Ed. Psy. Clin. Psych. Voc. Rehab. Guid. Couns. Child Dev. Spec. Ed. Recreation Speech Hearing Reading	▨	▨	
	Music Pharmacy Home Economics		▨	
Georgia Southern	Physical Education & Recreation		▨	
Temple	O.T.			▤
DeKalb Jr. College	Phys. Ed. & Rec.		▨	

CHART 6

PROJECTED ASSIGNMENT OF TRAINERS BY DISCIPLINE

INCLUDING ATHENS UNIT FY 1976

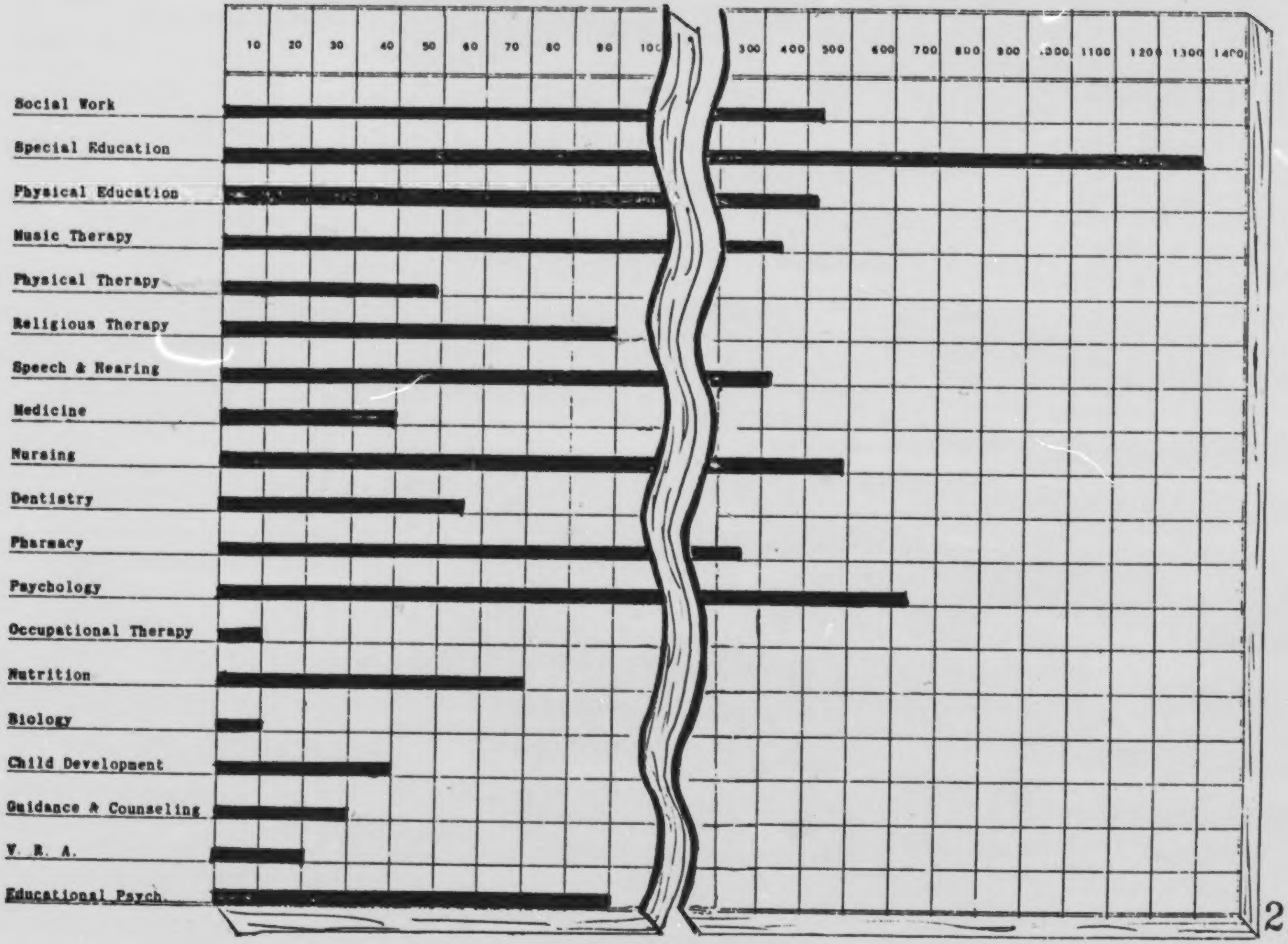


CHART 7

PROJECTED NUMBER OF TRAINEES BY LEVEL OF TRAINING

INCLUDING ATHENS UNIT FOR FY 1976

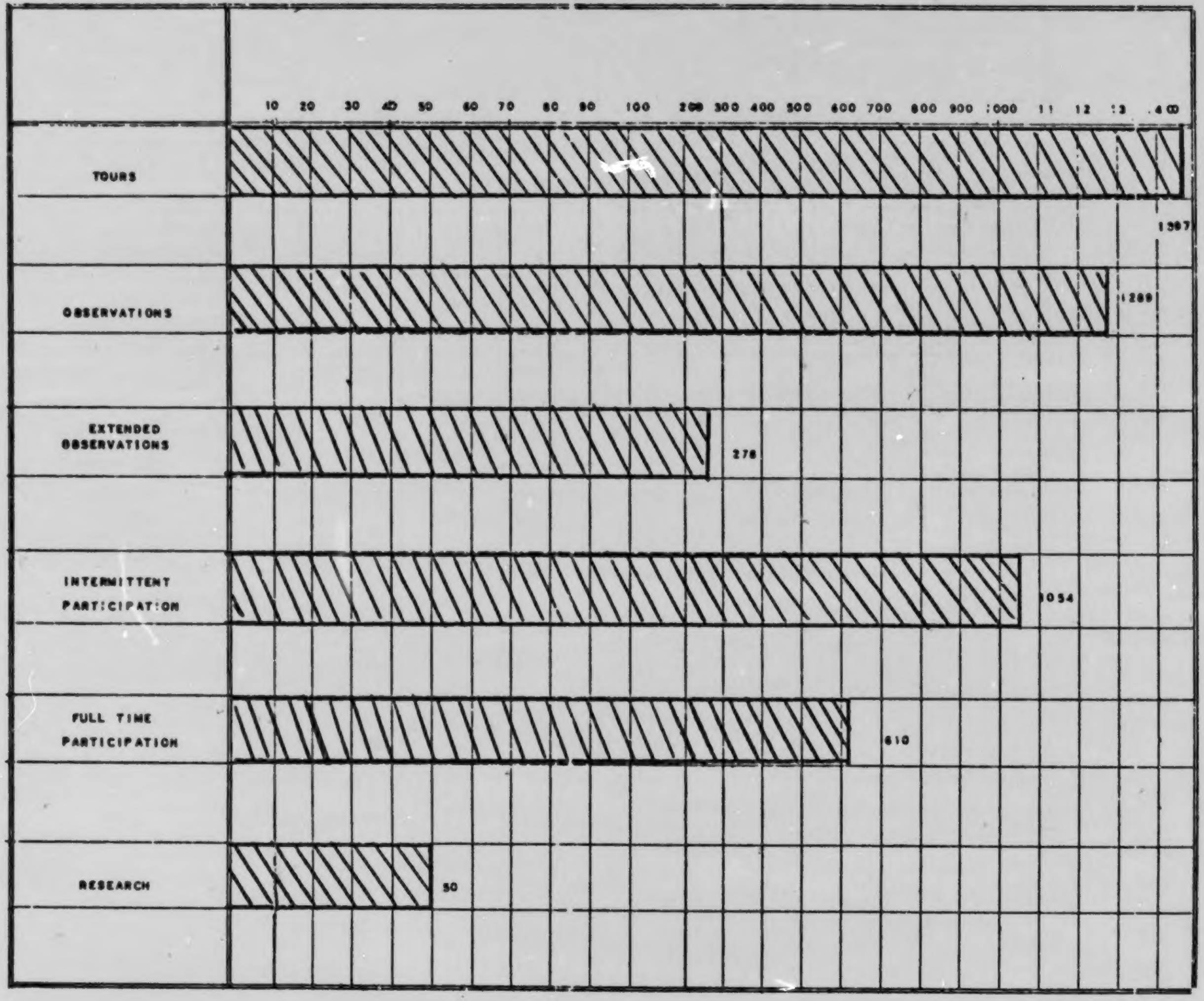
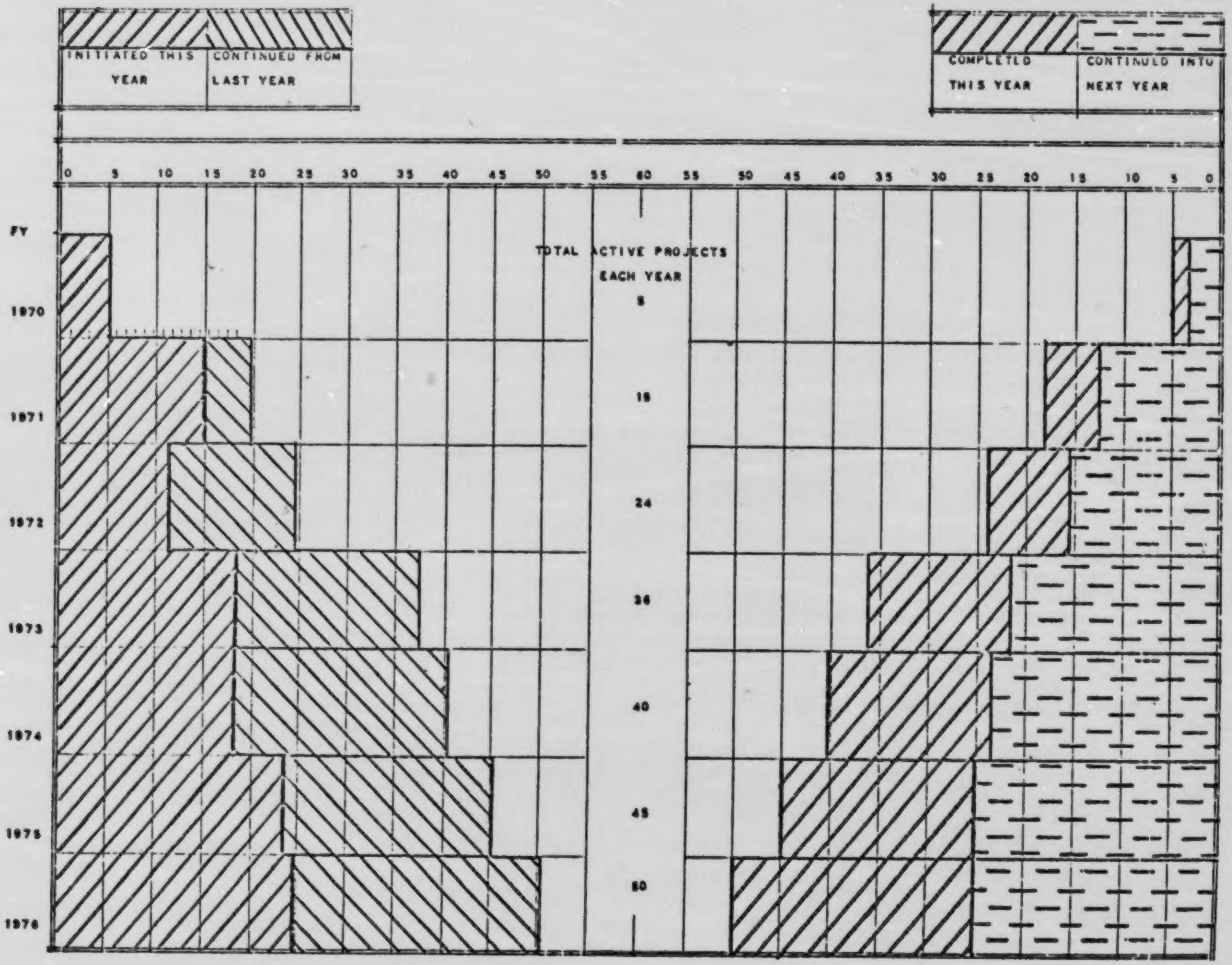


CHART 8

SUMMARY OF GRC RESEARCH ACTIVITY

1970 -. 1976



and applied research, originating from Center staff as well as university faculty and trainees. Thirty-two research projects were fully operable during this time period (see Chart 8 and Addendum 4).

Addendum 4

LISTING OF GRC RESEARCH PROJECTS ACTIVE DURING FY 1974

I. Applied: Research oriented at the improvement of

A. Diagnostic Techniques

University Originated

Addison, Carlyle, "Acoustic Impedance and Tympanometry with the Retarded"
Basmajian, J.V., "Muscular Factors in Hip Dysplasia"

GRC Originated

DeSana, Jeanne Beatty, "Cytogenetic Studies on Human Chromosomes in a Population of Mental Retardates"
Knight, Connie, "Deafness and Mental Retardation"
Knight, Connie, "Evaluation of Acoustic Impedance Audiometry"

B. Therapeutic Measures

GRC Originated

Dicks, Joseph, "Analysis of Factors Associated with the Degree of Cooperation of Mentally Retarded Subjects During Dental Procedures"

C. Training Methods and Materials

University Originated

Gray, Diane, "Investigation of the Effects of Vibration on the Body Schema of Retardates"
Hudgins, Michele, "Comparison of the Self-Concepts of EMR Students in Two Types of Educational Programs"

GRC Originated

Boles, Shawn and Alan Repp, "Response Differentiation and Stimulus Discrimination in Retarded Citizens with Down's Syndrome" Deitz, Diane and Shawn Boles, "A Comparison Study: Teaching Identical Tasks to Subjects Individually and in Groups"
LeClere, Roberta, "An Evaluation of Materials Comprising a Structured Motor Movement Kit"
Samuels, Thomas and Alan Repp and Shawn Boles, "An Analysis of the Effects of Various Response Cost Procedures in a TMR Classroom"

D. Program Development and Evaluation

GRC Originated

Kiett, Sylvia and Alan Repp, "Early Childhood Research and Demonstration"
Morris, Joan and Alan Repp, "Education Unit Project"

E. Institutional Management

GRC Originated

Kesler, Buford, "Attitudes Toward Severely Retarded Persons"
Tumblin, Alice and Dorothy Parkel, "Patterns of Student Performance Change in an Enriched Institutional Setting"

F. Community Services

GRC Originated

Parkel, Dorothy and Evelyn Messer, "Impact of Evacuation Crisis on GRC Students and Families and Import of Adjustment Factors"
Parkel, Dorothy and Alice Tumblin, "Survey of Needs for Community Mentally Retarded Services"

II. Basic: Research designed to elucidate

A. Characteristics of Mental Retardation

University Originated

Davenport, Richard, "A Study of Stereotyped Behavior in the Mentally Retarded"

The Community Education and Technical Assistance Program provided 54 courses in mental retardation and developmental disabilities. Nearly 1,500 packets of resource information were distributed to individuals on request. Over 7,400 hours of orientation to the field of developmental disabilities were provided to the general public. A "careers interest" program employs approximately 100 students each year. Since July 1, 1974, this program has been greatly expanded to include responsibility for the northern section of Georgia for:

1. Admissions to and discharges from five state residential facilities.

2. Assessment of the least restrictive alternative and assistance in placement for all developmentally disabled people.

3. Training of employees, consultation, and continuing education for day care centers and group homes.

4. Court evaluations and consultation to the courts.

5. Foster home evaluations, placement and monitoring.

6. Nursing home evaluation, placement, and monitoring.

7. Home consultation, family training, and crisis assistance.

8. Provision of adaptive equipment.

9. Respite care.

10. Hospitalization (both GRC and in private community hospitals) when families are unable to make proper provision in their home communities.

One indication of the increasing use of the resources of this program is the provision of 66 courses, lectures, and consultations to community programs during October and November 1974. The basic philosophy of the Georgia Retardation Center is that service, manpower development and research are interdependent. Only with adequately trained manpower, new and innovative program methodologies, and the continuing discovery of new information will patterns of residential care change as needed and be, in fact, part of a continuum of services for developmentally disabled people.

Retrospect and Prospect

A final conclusion on the impact of the UAFs on change would be premature. This is more an interim statement than an epilogue.

Several studies of the UAF network have begun, others are proposed. The so-called "Mayeda" Report and the federal audit (GAO) were partial evaluations of specific aspects. Other more complex qualitative and evaluative judgments will be tackled by the new Association of University Affiliated Facilities (AUAF) Long-Range Planning Task Force.[37] None of the statements in this chapter should preclude or restrain any activities or conclusions of these studies.

Exemplary Programs

Programs in nine UAFs highlighting the less well-known activities in service, research, and technical assistance have been documented here. There are 37 university-affiliated facilities (or separate units of one UAF) that are members of the AUAF, and others who are not members of this association. Still others are just beginning and exist only in programmatic form. All are recognized for their emphasis on interdisciplinary training. Some are mainly centers for training; others give almost equal emphasis to service, research, and technical assistance. There are more pressures for, and seemingly a trend toward, additional emphasis on provision of services.[38,39,40]

Is the Concept Logical?

A common misunderstanding of the role of the UAFs is that they should be all things to all people. This is illogical. The theory of interdisciplinary training seems quite logical. A national program which is still conceptually unclear is illogical. Mandating additional functions for the UAFs some at the expense of already well-established functions, without clear priorities and additional resources, defies logic. The exclusion of the UAFs from State Comprehensive Plans excludes their logical, full participation as a vital resource. A review of 16 State Comprehensive Plans, varying in publication dates from 1965–1978 (projected), showed that only one state made a specific reference to the UAFs in its plan.

Has Funding Been Adequate?

Severe restraints have been imposed on the UAFs because of uncertainties in year-to-year funding mechanisms and limited amounts of federal funds. Funding has been quite inadequate for larger service and technical assistance programs, less than adequate for training programs alone. While the UAFs never received the expected, or needed, level of federal funding, grantees of construction funds guaranteed in their applications that they had or would have funds to operate their facilities. When expectation or promise of support has not been met, the program is unfortunately blamed. In the decade since construction funds became available, priorities, concerns, and methods have changed. The UAFs have had to take on additional roles without adequate support.[41]

Have There Been Unrealistic Expectations?

Some people have expected the UAFs to provide programs tailored for every need. Rapid movement into residential care has been inhibited, in part, by overextension in other areas.[42] Costs of operating interdisciplinary training programs were initially underestimated, which has meant cutting back on the original scope of programs. Each funding agency has its own set of priorities, each bringing its own expectations of programs.[43,44] UAFs have the complex problem of meeting the expectations of four different systems, at different times and in different places—the university, the consumers, providers of services, and the national professional communities.[45]

Have There Been Unreasonable Constraints By State and Federal Bureaucracies?

Offers of assistance from the UAFs have at times been rejected. For instance, the regional HEW office requested the directors of UAFs in the region to help correct certain program deficiencies at Willowbrook Developmental Center. The lack of funding assistance by HEW and the State of New York, coupled with administrative resistance at Willowbrook Developmental Center, initially prohibited and later considerably hampered, assistance by these UAFs.[46] The diversity of funding sources and each agency's requirements and priorities present direct constraints not only on variety of programs but on populations served.[47, 48, 49] Definition of relationships between UAFs, State Developmental Disabilities Departments, and residential facilities is poor.[50] State Developmental Disabilities Councils frequently do not even recognize the existence of the UAFs. There seems to be a strange relationship between the University-Affiliated Facilities Branch, Developmental Disabilities Office, Department of HEW, and the ten regional Developmental Disabilities Consultants. The Washington office seems to have little or no authority over policy made and carried out at the regional level. As a result, it is difficult for everyone concerned to discern the intent of the Act and carry out the purposes of the law.

What Have Been UAF Successes and Contributions?

The unique contribution of the UAFs is a visible pool of professional manpower that has specific expertise in mental retardation and developmental disabilities.[51] They have had a major role in reflecting the philosophies of "deinstitutionalization" and "normalization." The role of recruitment should not be underemphasized.[52] Fifty-nine papers were presented at the 98th Annual Meeting of the American Association on Mental Deficiency at a special session on successful UAF programs.[53] It is too soon to say what our greatest successes have been. Our real contributions will probably be better measured ultimately in terms of professional leadership supplied by our trainees. The UAF should continue to make a major contribution by feeding both knowledge and specialized personnel into the field.[54]

Where Should Additional Emphasis Be Placed?

The impact of the UAFs on patterns of residental care could be increased significantly by focusing on direct problem issues. There is a need to get more involved in operational and organizational research. Guardianship and advocacy should be emphasized and incorporated into affiliations with schools of political science, public administration and law. Stronger liaisons should be established with other agencies to help with inservice education of direct care personnel (residential facilities of all types have a common problem), community education, and technical assistance. Program goals should be established for each UAF to enhance and facilitate the efforts of others within the total network.[55] A carefully designed scientific study must be done to find out whether a person trained in a single discipline who goes into a multidisciplinary job setting operates any less effectively than does a UAF graduate in the same setting for the same period of time.

Some Unanswered Questions

Does an interdisciplinary setting have greater merit than traditional sorts of training and educational experiences? Does interdisciplinary training lead directly to superior skill? Have the UAFs had an impact on public information and policy? Are they shaping public attitudes? Will exposure to and training in the philosophy of the least restrictive alternative have a real impact on deinstitutionalization? What are the responsibilities of the UAFs to residential service systems? What are the priorities of the UAFs? Are the cost benefits commensurate with other programs?

To answer such questions, a measurable, comparable, and reasonably consistent data base must be established within the UAF network. The AUAF is now proposing a national UAF data base, incorporating computer technology and evaluation methodology. We hope this project will be coordinated with another in a joint effort to establish both a computer-based information system and a program evaluation component in the system.[56]

Data should include certain specific questions about trainees, service delivery systems, and elements of individual UAF programs,[57] source of funding and its requirements, and the role of service within the particular UAF.

Finally, if UAFs are to continue to contribute to the field of mental retardation generally, and to be an instrument of change in residential service systems, they must have methods of assessing accountability. Dr. Herbert J. Grossman of the Illinois Pediatric Institute suggests the following methods:

1. Identify service users and their problems.

2. Evaluate costs of services and their effectiveness.

3. Consider options that deliver more for less money.

4. Keep systems flexible for changing needs.

5. Determine the information that will be needed and how to use it once collected.[58]

We have begun to lessen the distance between training practitioners and their actual post-training practice. The initial concept of the university-based training facility has served a useful purpose. Perhaps it is time to move on—to "deinstitutionalize" the UAFs. For the existing UAFs, we should consider extension into the community with multiple training sites—perhaps an extension service like the one developed by the departments of agriculture early in this century. It might well be appropriate to place new UAFs directly in community service settings. After all, "Change is a synonym for learn, to Change is to learn."[59]

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Biography

JAMES CLEMENTS was born in Pineview,Georgia in 1931. He earned his B.A. degree from Emory University and his M.D. degree from the Medical College of Georgia. He took his advanced training at Temple University and at Yale University. He is a graduate of programs in civil management of the Institute of Government, University of Georgia.

He was the medical director and later assistant superintendent of Gracewood State School and Hospital. Before becoming director of the Georgia Retardation Center in 1964, he was director for comprehensive planning in mental retardation for the State of Georgia. Dr. Clements currently holds academic appointments in pediatrics, psychiatry, neurology, and mental retardation at Emory University Medical School, the Medical College of Georgia, and Georgia Baptist Hospital.

Dr. Clements is a member of the President's Committee on Mental Retardation, serving on its task force on humane services. He has been a consultant on the committee's fact book, *Mental Retardation: The Known and the Unknown*, and a similar compilation by the Office for Handicapped Individuals. He is a member of the board of trustees of the Mental Health Law Project and consultant to the U.S. Department of Justice. Dr. Clements is past President of the American Association on Mental Deficiency.

12. The Joseph P. Kennedy, Jr. Foundation

Eunice Kennedy Shriver

Unlike many foundations which begin with a source of funding and then search for programs to support, the Joseph P. Kennedy, Jr. Foundation has had a firm objective from the outset: to seek the prevention of mental retardation by identifying its causes and to improve the means by which society deals with its citizens who are already retarded.

The Foundation was impelled in this direction by the experiences of the Kennedy family with my sister Rosemary, who was born mentally retarded. At her birth and during her childhood, there were almost no medical, educational, or community services to guide and support the families of the mentally retarded. No federal legislation provided funds to aid the retarded. No medical schools or research centers were devoted to the discovery of the causes of retardation or to development of its cure. Such institutions as did exist were storehouses of the unwanted, with no programs of training, recreation, or rehabilitation to relieve the helplessness and despair of the residents or their parents.

To have borne a retarded child was considered a stigma and a punishment. And the only release from this stigma was concealment at home or abandonment to an institution from which there was no release.

From its earliest days, the Foundation recognized that it could never provide enough money to change the status of the retarded single-handedly. Therefore, the guiding strategy of the Foundation has been to use its funds and its influence in those areas in which a "multiplier effect" could be readily achieved: to develop models to capitalize on innovation; to provide seed money to capitalize on flexibility; and to promote public awareness to capitalize on the Foundation's ability to capture the attention of the American public.

The role of a private foundation was perceived not as a substitute for other public or private activity but as a change agent and stimulator of increased awareness and action by both government and private agencies.

Thus, over the past generation, the Foundation has been instrumental in increasing greatly the interest of universities, hospitals and institutions in mental retardation and encouraging their emphasis on basic and applied research in the field.

As a consequence, grants from the Foundation have been multiplied many times over through additional funds from governmental and other public and private sources. Interest in mental retardation generated by the Foundation led to the creation of the President's Committee on Mental Retardation, the introduction of landmark legislation beginning with the Mental Retardation Facilities Act of 1963, the establishment of the National Institute of Child Health and Human Development, the planning for the Headstart program, and to major changes in civil service regulations, enabling the hiring of more than 15,000 mentally retarded men and women.

While substantial sums have been given by the Foundation for buildings and facilities related to mental retardation—especially in the early years when they were desparately needed—the Foundation's most significant investments have always been in people.

People who have performed basic research into the causes of mental retardation.

People who have worked to develop cures for mental retardation.

People who have improved the treatment, care, education, and rehabilitation of the retarded.

People who have influenced legislation and public opinion concerning the mentally retarded.

People who have multiplied their Kennedy Foundation grants many times over by attracting additional public and private funds for their work with the mentally retarded.

As a result, while there are schools, clinics, laboratories, and institutions whose bricks and mortar have been purchased through Kennedy Foundation funds, the Foundation's principal influence has been on the quality of research, scholarship, administration, teaching, civic and political leadership directed towards the field of mental retardation in all its aspects.

While the Kennedy Foundation itself has remained extremely small in staff and limited in resources, it is generally agreed that because of programs initiated and maintained by the Kennedy Foundation:

Literally dozens of the most capable men and women in the biological sciences, genetics, medicine, law, ethics and related fields are now working to solve the problems of mental retardation and those deriving from this field which affect the rest of the population.

A new generation of students and professionals is being influenced to devote its talents and resources to the field of mental retardation not only through teachers and counsellors but by fellowship programs supported currently by the Foundation.

Literally millions of dollars in Federal, State and private funding that would have gone elsewhere have multiplied the impact of the Kennedy Foundation investment in people. A partial roster of the recipients of Kennedy Foundation grants would include some of the most prominent research scholars and clinicians in America, including Robert E. Cooke, M.D., Vice Chancellor for Health Sciences, University of Wisconsin; Hugo Moser, former Medical Director of the Fernald School in Massachusetts; Paul Ramsey of Princeton, the first eminent ethicist to work in a medical setting; Harry Gordon, Director Emeritus of the Rose Kennedy Center at Georgetown Medical School—senior statesman in mental retardation research; Guy McKahn, Joseph P. Kennedy, Jr. Professor of Neurobiology at Johns Hopkins; Albert Dorfman, Director of the Kennedy Laboratories at the University of Chicago.

The fact, simply stated, is that from practically no research and no interest 25 years ago, when the Kennedy Foundation was established, the people recruited to mental retardation study and research constitute one of the most distinguished, creative and productive interdisciplinary bodies in the world today.

To recognize the quality of this leadership and to sustain its continuity, the Kennedy Foundation created its International Awards program in 1962. Presented five times since their inception, the Awards have become widely recognized as "the Nobel Prize" in the field of mental retardation. They are given to men and women who, in the opinion of a distinguished panel of judges, have performed outstanding services to the mentally retarded of the world in the categories of scientific research, service and leadership. Past Kennedy Laureates include such internationally recognized scientists and humanitarians as Jerome LeJeune, Harold Skeels, Maria Egg, B. F. Skinner, and Mother Theresa of Calcutta.

When the Foundation set its objectives and its strategies for achieving them, no facilities with any degree of excellence existed for the study of mental retardation and the clinical treatment of the retarded.

This was given top priority. Over the past quarter of a century, beginning with the establishment of Kennedy Centers in Brighton, Massachusetts and Santa Monica, California for improved diagnosis and treatment of mental retardation, research and clinical centers have been organized with the encouragement and support of the Foundation at Johns Hopkins University, Georgetown University, Harvard University, Stanford University, the University of Wisconsin, the University of Chicago, George Peabody College, Yeshiva University, the University of Colorado and Miami University.

The programs at these institutions have been broadly diversified, including both long and short-term projects, high-risk and immediate-yield research, programs of prevention, diagnostic treatment and training, of services for both mildly and severely retarded, as well as interdisciplinary programs in medicine, ethics and law. For example:

- Kennedy Scholars at Einstein have provided scientific leadership in neurobiology.
- Scholars at the University of Chicago are pioneers in the use of tissue culture techniques and the diagnosis of genetic disease.
- Johns Hopkins identified and established programs for the prevention of Tay-Sachs disease; the virus causing hepatitis has been isolated; and major steps are being made in understanding the nervous system.
- Harvard and Georgetown are bringing together geneticists, ethicists, lawyers, demographers and physicians with the hope that new knowledge can be obtained which will lead to the development of a value system which protects the rights of the unborn, the retarded and the handicapped and

which provides new insights through which wiser decisions of life and death may be made.

- At Peabody, an attempt is being made to wipe out cultural retardation by improving the behavioral and cultural environments and by influencing the acquisition of knowledge by young children to lead to more successful functioning.
- Miami has been concerned with the rights of the retarded under the law and the application and development of laws pertaining to the retarded.

In addition to these major centers, the Foundation has also funded institutes, schools and centers for the diagnosis, treatment and education of the retarded in Massachusetts, New York, Illinois, California, Wisconsin and Washington, D.C., and sponsored significant research at such institutions as Marywood College where practical studies in social welfare are being developed and tested to determine how families, especially the brothers and sisters of the retarded, can be helped to adjust to the often severe problems of the handicapped in the home.

Prior to the establishment of the Foundation's university-related research centers, not a single course in mental retardation was given in any university. Research was confined to a few state institutions handicapped by a chronic shortage of funds and limited scientific capability. No scholars of merit would risk their reputations in such a field. Over the years, however, biomedical research centers were created in leading universities, and government agencies have been influenced to follow suit, establishing similar centers at UCLA, North Carolina, Indiana, Kansas, Washington State and elsewhere.

Nobel Prize winners have turned their attention to the molecular basis of mental retardation. Geneticists have looked for the first time at the tissue culture of cells of the mentally retarded. Answers to basic problems in biology, sociology and education have been found in studies of the mentally retarded—even clues as to the cause of cancer and of aging. Principles of individual difference have been derived from the educational research on the mentally retarded to the benefit of normal school populations.

In the last 10 years alone, major breakthroughs in virology, neurobiology and genetic counselling have taken place in the Foundation's university centers and the $10 million Foundation investment during this period has returned over $200 million in construction grants, research project awards, fellowships and training. This is due entirely to the quality of people attracted to the field of mental retardation and their dedication to the aims of the Foundation.

At the same time that the Foundation was provided seed money and developing models for institutional programs in research, education and training, it recognized that additional support from government and private agencies would only be forthcoming if the public encouraged and endorsed such efforts.

Beginning in 1965 and continuing for three years, the Kennedy Foundation funded jointly with the Department of Health, Education, and Welfare and the National Association for Retarded Citizens, a massive public information program in mental retardation conducted by the Advertising Council. Over the period of the campaign, more than $30 million in free advertising space and time was donated by local and national media, 4 million booklets on mental retardation were ordered through the advertisements, and business and industries distributed more than 40 million leaflets to customers and employees. Surveys conducted both before and after the campaign showed a greatly increased public interest in and awareness of mental retardation attributable to the wave of information carried for the first time by America's media.

With the conclusion of the Advertising Council program, the Foundation has greatly increased its own public awareness activities, receiving great support from national and local media alike in reporting not only the problems of the mentally retarded but their significant achievements and contributions as well.

While the Foundation was supporting and encouraging basic research and clinical and diagnostic progress on the university and medical school level, it also launched several model programs of its own creation in the areas of vocational rehabilitation and physical fitness. These programs, too, have served as change agents—altering the concept of vocational rehabilitation for the retarded and creating a dramatic and irreversible improvement in the health and physical fitness of mentally retarded children and young adults.

In 1964, the Foundation became concerned that mentally retarded adults in sheltered workshops were being required to perform largely menial, repetitive tasks at substandard wages. The

Foundation theorized that the retarded were capable of a higher order of employment, that the sheltered workshop should not be an end in itself but a stepping stone to a productive life in the community, not in an institution.

Aided by a three-year grant from the Office of Vocational Rehabilitation of the Department of Health, Education and Welfare, a model nonprofit corporation, Flame of Hope, was established to demonstrate the capabilities of the retarded to produce acceptable, competitive products.

During the demonstration period, Flame of Hope produced and sold more than $5 million worth of candles, perfumes and other products made entirely by mentally retarded persons.

As a result of the program's success in proving that many retarded men and women are capable of performing well in creative jobs, the ownership of the Flame of Hope corporation was turned over to the participating workshops in 1971, becoming the first company in the world to be owned by mentally retarded persons and marketing products which they themselves produce.

In the mid-1960s, the Foundation became increasingly concerned with the problem of physical fitness among the retarded. Grants were given by the Foundation to permit teachers of physical education to receive special training in the needs of the mentally retarded, and a national testing and award program was initiated in conjunction with the American Association for Health, Physical Education and Recreation, modelled on the President's Physical Fitness Award.

Research conducted in the early 1960s demonstrated conclusively that the mentally retarded were not being given the benefits of physical training and play. Surveys showed that more than 50 percent of all mentally retarded children were receiving less than one hour per week of organized physical activity and 25 percent were receiving none at all. In most communities, access to swimming pools, playgrounds and gymnasiums was denied to the mentally retarded by local ordinance. Schools and institutions for the retarded, overcrowded and understaffed, were providing little if any opportunity for exercise and physical training. Even professionals in the field were dubious that mentally retarded children had the strength, the stamina or concentration to take part in the kinds of physical activities so beneficial to normal children.

In response to the pressing need for change in the area of physical education, the Foundation created the Special Olympics program to serve as a model for greatly expanded sports and recreational programs in schools, communities and institutions throughout the world.

In the summer of 1968, the First International Special Olympics Games were held at Soldier Field in Chicago. More than 1,000 children came from all over the United States, Canada, and even France to participate in a variety of track and field and swimming events. They were of all ages and all degrees of mental and physical disability, from the profoundly to the marginally retarded. Each child was given the opportunity to compete with children of his own age and demonstrated capability so that none would be denied the opportunity of winning.

Fully sanctioned by the United States Olympic Committee and endorsed by all major professional organizations of special educators, recreators, coaches and athletes, the Special Olympics has grown from that single meet to a year-round sports organization, the first and largest of its kind in the world, involving more than 400,000 retarded youths, 150,000 volunteers, organized chapters in every state, the District of Columbia, Canada, France, Switzerland, Mexico and a growing number of other countries.

Largely because of Special Olympics, communities are now opening their recreational facilities to the mentally retarded and schools and institutions conduct year-round Special Olympics training programs, based on rules and manuals produced by the Foundation with the cooperation of organizations like AAHPER, the AAU, the National and American Basketball Associations, the National Hockey League and other professional and amateur sports groups.

Among the 15,000 individual training programs, meets and games which take place each year are winter Olympics, basketball, bowling, floor hockey, swimming and diving meets and tournaments, track and field meets involving the mile race, the 400-yard relay and the pentathlon together with wheel chair events and special races for the severely handicapped and the blind.

Recognizing that parents and siblings rarely become involved in sports and recreation activities with the mentally retarded child, the Foundation in 1974 developed and tested nationwide a new model program of physical activity and family play called

"Families Play to Grow." By the end of 1974, approximately 100,000 children were taking part in Play to Grow activities with parents, brothers and sisters, teachers and aides in more than 1,000 homes, community groups, public and private schools and institutions, day care centers and camps.

While the genetic, biological, clinical, educational, vocational and physical aspects of mental retardation have occupied the attention of the Foundation over the years, there has been a growing awareness that even more important, perhaps, than the medical or sociological consequences of mental retardation are its ethical considerations.

In an increasingly cost-benefit-oriented society, where utility is regarded as the prime value, how can public expenditures for the retarded be justified? Scientists are increasingly demanding on "moral" grounds the prenatal elimination of a Mongoloid infant. In the maternity wards of some of the most prestigious hospitals, infants with disabling but nonfatal handicaps are being denied the procedures which would enable them to survive. The rights of the handicapped are challenged by the increasing demand of society to be free of unnecessary and unwanted burdens. Genetic engineering challenges the imagination even while it threatens the future of many citizens. The use of the retarded as experimental subjects or even as donors of critical organs is being accepted as ethical in many parts of the world.

Beginning with its sponsorship of the first International Symposium on Medical Ethics, "Choices on Our Conscience," in Washington, D.C. in 1971, the Foundation has embarked on a major intellectual and financial effort in the broad area of medical ethics.

Just as the Foundation concentrated on biomedical and educational research in the 1950s and 1960s, so in the 1970s the Foundation is emphasizing the bio-ethical aspects of scientific research and medical practice.

As before, emphasis is being placed on people and on the development of model programs which the public and private sectors can then adopt and extend more broadly.

Fellowships in medical ethics have given highly qualified professionals in the fields of medicine, law, theology, the neurosciences and nursing the time and resources to become leaders in the study and teaching of medical ethics.

Two major centers for such studies have been funded by the Foundation—the Joseph and Rose Kennedy Institute for the Study of Human Reproduction and Bioethics at Georgetown in Washington, D.C. and the Kennedy Interfaculty Program in Medical Ethics at Harvard.

In addition, the Foundation is sponsoring intensive, short-term seminars in medical ethics which are attracting medical practitioners from all parts of the country.

To raise the public's awareness of medical-ethical problems and improve the quality of the dialog on these issues, the Foundation has produced several films on such crucial subjects as "The Right to Survive," "The Right to Let Die," and "The Right to Reproduce." Available for purchase or rental, at cost, to schools, colleges, hospitals and institutions, these films have been seen and discussed by more than half a million people and are now part of the curriculum in more than 100 graduate and undergraduate programs in medicine, theology, nursing, sociology, law and ethics.

With educational leaders developing curricula for students in law schools, medical schools, and schools of theology—the no man's land between medicine, law, and ethics is being bridged in many of the same distinguished institutions as before. In an unlighted, unmarked area so essential to our survival as a humane society, the Foundation is seeking to interest other foundations and institutions in illuminating the issues and training the moral, intellectual and scientific leaders of the future. Although this program is still very new, there has, once again, been a dramatic response to its objectives. Before too long, it is hoped that almost every professional discipline will ground its students in the criteria by which truly ethical decisions of life and death may be made.

The human rights of the retarded, the handicapped, the aged, and the infirm are being threatened as never before in our history. And the way in which society deals with those who have the least utility because of physical or mental disabilities will determine how it will treat others out of power and favor when the competition for survival becomes more acute.

The Kennedy Foundation hopes that just as it has attempted to generate a scientific and educational revolution centered on the mentally retarded, it can now help seed an ethical revolution which can move beyond the retarded to help create a better and more just society for all.

For, as the great French psychologist and Kennedy Laureate, Jean Vanier, has said, "A society which does not care for its weaker members is a society which lives in an illusion. A society which rejects the weak is a society committing suicide."

By emphasizing the obligations of the strong to protect and enlarge the rights of the powerless, it is the hope of the Kennedy Foundation to counter these destructive tendencies and to help create a society where, in the words of President Kennedy, "the strong are just and the weak secure."

Biography

EUNICE KENNEDY SHRIVER was born in Brookline, Massachusetts. She received a B.S. in sociology at Stanford, and honorary degrees of L.H.D. at Manhattanville College of the Sacred Heart, Litt.D., at the University of Santa Clara, L.H.D. at D'Youville College, and an L.L.D. at Regis College. During the war she worked with the special war problems division of the State Department. In 1950 Mrs. Shriver became the executive vice president of the Joseph P. Kennedy, Jr. Foundation; she was a consultant to the President's Panel on Mental Retardation and is a recipient of the Lasker Award.

13. Change by Persuasion: The Work of King Edward's Hospital Fund for London

James Elliott

In 1969 began a period of great disquiet about mental handicap services in the United Kingdom. That year saw the first of what where to be several adverse official reports on large mental handicap institutions. An extremely critical report on conditions in a large hospital for the mentally handicapped[1] had been for some time under ministerial consideration; the incoming Secretary of State for Health and Social Services, the late Richard Crossman, decided to publish in full. It was a decision calculated to stimulate a public call for major change.

The result was interesting; the public said: "So this is how the professionals treat the mentally handicapped in Britain!", to which the professionals rejoined: "We don't like this service either, but this is what you have asked us to provide—cheap custody."

The professionals felt sure that the public's desire for improvement in the mental handicap service would last only as long as its recollection of the latest institutional scandal. Some contended that the existing type of service, based on large institutions and patchy community services, would be perfectly all right provided there were more money to run it. Preservationists advocated bigger and better institutions; demolitionists advocated their immediate destruction, and looked to Scandinavia for a packaged answer. In the center stood the radical reformists, aware of the stirrings of reform throughout the world, anxious to improve the content of the service but not adopting ideological postures, their voices hardly heard above the noise of the slogans which the demolitionists and the preservationists were shouting at one another.

The International League of Societies for the Mentally Handicapped had made a fine declaration in Jerusalem about the rights of the mentally retarded, and now this had been adopted by the United Nations. Isolated copies of *Changing Patterns in Residential Services for the Mentally Retarded*[2] began to make their appearance. But like the Bible, *Changing Patterns* could be made to prove anything. It enabled British preservationists to claim that their institutions were not as bad as those in the USA; it enabled the demolitionists to claim that the old institutional pattern was doomed; and it encouraged the radical center with its cry for reform.

In fact, after the watershed of 1969, change began to take place through a number of agencies. This chapter describes the work of one of these agencies, King Edward's Hospital Fund for London.

It is a matter of historical accident that Britain's institutions for the mentally retarded are designated as hospitals and are thus placed in the hospital service. The reasons for this are interesting but are not immediately relevant to this chapter. It was, however, in one sense a fortunate accident in that it permitted the King's Fund to take an interest in mental handicap. For the Fund's original object was defined in 1907 as "the support, benefit, or extension of the hospitals of London." Had the services for the mentally handicapped been part of the general social or educational services it is doubtful whether the Fund could legitimately have entered upon the scene.

King Edward's Hospital Fund for London

The fund was established in 1897 by Edward, Prince of Wales, afterwards King Edward VII. The purpose was to help the hospitals of London. With a capital value of 26 million pounds ($60 million), it is one of the bigger charities in the United Kingdom. Nearly half of its annual income of 750,000 pounds ($1.6 million) goes in grants for experiment and enquiry, in direct grants to hospitals to improve buildings and amenities, and to voluntary organizations for development or toward their running costs. The remainder supports the King's Fund College, which provides management training for senior health service staff of all professions; and the King's Fund Centre, an information and conference unit, in which the Mental Handicap Project, to be described, came to be based. Because of the Act of Parliament of

1907, the Fund's direct grants are still mainly confined to places in Greater London, but there is no geographical limit to its services, as opposed to its grants.

The Fund is not well known to the public; only occasional references are seen in the national press. No appeals for funds are made, and the Fund relies almost entirely upon income from its invested capital. Perhaps the Fund's best known characteristic is its preparedness to help hospitals to tackle current problems and to anticipate change. Often it buys time for hospitals, enabling a pressing need to be met or an innovation to be developed, perhaps some years before the idea can be respectable enough to be eligible for official funds. Its interest is in the organization and delivery of services rather than in their clinical content.

A very strong asset of the Fund, one which will be particularly appropriate to this chapter, is its reputation for informed neutrality. Whether at the College or at the Centre, it provides a neutral territory in which people from all services and all professions, and very often consumer groups as well, can meet together to discuss topics which would be politically or temperamentally impossible in any more partisan setting. It is not only the professionals in the health service who value this freedom and neutrality; it is equally well, if not more, valued by the Ministers and their civil servants who use the King's Fund as a listening post and sometimes as a place where they themselves may contribute ideas in an informal way.

Whereas for several decades the main interest of the Fund lay in acute hospitals and their associated supporting facilities, over the last decade or two interest has spread to a number of other fields: for example, the care of the elderly, the mentally ill, the development of voluntary services in health care—all of which, though medical in content, have a considerable social fringe. So it was not altogether unexpected when the Fund began to consider how it could make some useful intervention in the field of mental handicap. As a result, in 1970 the Fund decided to appoint an administrator (the writer of this chapter) "who would collaborate with hospital boards and committees, and other authorities and organizations in their plans for the improvement of services for the mentally handicapped."

The Mental Handicap Project

It is well known that to deliver a good mental handicap service requires the collaboration and coordination of a number of disparate professions. Very often, good service is inbibited by insistence on professional demarcation lines. In Britain, the situation is further complicated by the fact that the professionals are split between three official services (health, education, and welfare) not to mention a wide scattering of voluntary societies and organizations. Such a situation would be likely to cause conflict at any time, but the risk is enhanced during a period, such as has been described, of public dissatisfaction and professional dismay, concurrent with a world tide of deep philosophic change.

In this troubled scene, the King's Fund, a neutral organization, put its new project into the hands of a neutral; an administrator who did not belong to any of the competing and disputing professions. The project team consisted of only two people: the project director (the writer) and an administrative secretary. Much later, they had the part-time help of one other person. The small team had terms of reference which were extremely flexible: almost any work could be undertaken, provided the project staff felt it likely to result in better services to the mentally handicapped. The team was based at the King's Fund Centre, which was already housing a number of special projects, and in addition was able to offer not only a normal administrative back-up but also a specialized library, a system of scanning journals, a printing department, an exhibition and design department, and an excellent catering department. Furthermore, the Fund, by the very nature of its work, already had a vast acquaintance of people in the health and social services field. With a back-up service like this, the team was able to get down to business almost as soon as it arrived. The project director had complete autonomy, provided only that he kept the Fund informed of the general line of direction of the project and its budgetry implications and subject to the normal administrative rules of its host, the King's Fund Centre.

The project quickly began to respond to demand, some of which is described below: but could it also originate enquiry and begin to define priority needs? No doubt the team could assist procedural and technical change and indeed did so. But could it change the very pattern of service, which had been established partly by accident of history and partly by conscious act of the politicians? The Fund's whole method of operation was apolitical. The project could exert no professional pressure. It did not represent parents. It was not the figurehead of a pressure group. It had no research or scientific arm. It controlled no section of the press, nor had it any standing in the political lobbies. The project was unable to take up individual cases of difficulty or hardship or to bring court action. It was not even identified in the eyes of the general public with mental handicap. It is doubtful whether most of the public even knew of the Fund's existence.

Here is the paradox. How could the King's Fund, a neutral and nonpolitical Foundation, with no executive authority over any part of the health or social services and no commitment to any professional or consumer group, become an instrument of change? Did it in fact achieve change? What happened?

The Activities of the Project

The initial objectives were as follows:

- to provide neutral territory for the discussion of mental handicap strategies;
- to facilitate the exchange of ideas among people of different professions working in different services;
- to sponsor training and education of inservice staff;
- to advise on staffing problems;
- to effect a link with other organizations working in the field of mental handicap;
- to assist the process of change by encouraging the development of more modern management systems in institutions.

This is what happened.

Providing Neutral Territory

The project bas facilitated debate on the question which affects all mental handicap services: should they be based on a medical model or a social or a educational one? At the outset, meetings expressed an extreme polarity of views, and anger and frustration were often the outcome. As the project got into its second and third years, it was noticeable that discussion became far more objective. Staff who had worked for a long time in the old system now questioned how change could be achieved, rather than whether it ought to be achieved.

Another difficult issue was the question of training of care staff. Unlike some countries, Britain has had for many years a core of trained care staff. They are nurses who have been especially trained for work with the mentally handicapped. Many of them would wish the content of their training to be changed, since they feel that this is at present too clinically orientated, but few of them are ready to lose the honored status of nurse and be placed instead in the largely unknown and undesignated category of care staff. The existence of a neutral platform has permitted the nurses to come out of their trenches and to discuss objectively where their training falls short, and whether they are nurses at all in the accepted sense of the word.

It has been possible to consider the way in which traditional hospital management systems impair the delivery of a multidisciplinary service and to discuss new systems much more openly and freely than would have been possible five years ago.

There existed considerable distance between the official services and the voluntary societies; largely, because neither knew much about what the other was doing. The creation of a neutral platform has brought members of the voluntary societies into meetings and discussions as ordinary participants, rather than as people with special labels on them. Thus, they have developed a much better understanding of service problems, and the service staff have begun to see the kind of contribution which the voluntary societies can usefully make.

At a stage when the Department of Health has been concerned with such broad strategic matters as community care versus institutional care, or whether there ought to be a national service for the mentally handicapped, or the way in which the recent reorganization of the National Health Service should affect mental handicap—in all these matters,,government departments have been able to test the service temperature by attending meetings at the King's Fund Centre. These are but a few examples of the way in which this neutral platform has been used.

Exchange of Ideas

At the outset it must be explained that the whole of the work of the King's Fund Centre, mental handicap or otherwise, has an interdisciplinary basis. The project has organized conferences for groups of about 100 people; study groups for shopfloor workers numbering about 40; seminars for invited senior staff, usually resulting in the publication of discussion papers; staff workshops on particular projects—for example, play for the severely handicapped, or programs for the profoundly retarded, or problems of violent and aggressive mentally retarded people. Whenever an opportunity has presented itself, we have encouraged speakers from abroad to bring in another point of view.

Major exhibitions with associated audio-visual programs have been put on relating to the environment of the mentally handicapped, to the improvement of old institutions, and to the organization of play and toys for retarded people. An illustrated publication, *Room for Improvement*,[3] which explains today's mental handicap strategies and the way in which environment and staff attitudes can affect development, has been produced. The project director has been enabled to visit a number of countries in Europe and North America.

A quarterly *Mental Handicap Bulletin* is produced on subscription, with articles on mental handicap culled from journals all over the world and sometimes specially commissioned. Bulletin has subscribers in many parts of the world and over 1,000 copies go to workers in Britain. The growth of the mailing list for Bulletin has provided a key vehicle for general mental handicap mailing, and a number of voluntary societies and institutes make use of this facility.

Inservice Training

The King's Fund Centre is not staffed as a training institute but it has sponsored a number of useful training ventures. It regularly organizes study-workshops on specific topics for small groups of staff. The King's Fund College has made it possible for the project to hold small residential seminars on mental handicap and these in their turn have influenced the College in its own approach to education in health care generally. In addition to study groups at the Centre and the College, every opportunity is given for similar study groups to be organized in colleges and university departments of adult education throughout the country.

Experimental inservice training schemes have been sponsored, all aimed at changing the orientation of existing institutional staff. A system has been developed by which a study pack with an audio-visual program can be mailed off to small groups in the field to permit study of particular topics. Support meetings are held for the regional project officers employed by the state service, whose job is to try to raise the level of mental handicap service in their respective regions.

An especially strong relationship has been developed with Britain's only Institute of Mental Subnormality and, through the agency of the project, the Fund has made a special grant to enable the Institute to develop practical schemes of inservice training in behavior modification and a further grant to encourage training for physiotherapists specializing in mental handicap. A local college of education has received a grant to permit an experimental five-week course in arts, music, and movement for staff working with the most severely retarded individuals. A project has begun for educating in the facts of mental handicap those authority members and officials whose decisions impinge upon the welfare of the mentally handicapped but who have an imperfect knowledge of today's strategies.

It will be seen that all these training initiatives are in the direction of experiment or pilot schemes or sponsoring other organizations to undertake the work. Always the hope is that the official organizations will follow suit once they see a good idea demonstrated.

Advice on Staffing

A typical example of work in this field is an examination of the true role of the nurse in mental handicap mentioned earlier. Another burning question is whether the psychiatrist has a role in mental handicap services and what his relationship ought to be with the pediatrician, the child psychiatrist and the general physician in this field. In addition, what is the total relationship of the medical profession with the other professions involved in mental handicap? This whole area is now coming under discussion, using the project's neutral platform.

Effecting a Link With Other Organizations

Good links have developed with the three major voluntary societies in Britain and also with a number of smaller service-giving organizations or societies. There is a link with the Institute of Mental Subnormality and with the Institute of Research into Mental and Multiple Handicap. Collaboration with the Centre on Environment for the Handicapped[4] has resulted in one joint publication[5] and also informal cooperation on a number of other publications and activities.

To avoid fragmentation of professional effort, the project sponsored an open meeting at which the possibility of an Association of Professionals for the Mentally Handicapped was mooted. As a result it was decided to go ahead and the project director has acted as honorary secretary. The Association now has a very considerable membership and has just organized its first Annual Congress, possibly the first occasion in Britain on which there has been a truly collaborative gathering involving all the professions, all the services, the voluntary organizations, and the parents. The King's Fund permits the Association to use the King's Fund Centre as its organizational base, permits the director and his assistant to undertake administrative and secretarial work for the Association, and permits the use of duplicating and printing machinery and all other office facilities at a modest charge.

Thus the existence of the Fund's project has enabled a bridge-building noncompetitive organization to establish itself, and the good results of this are already appearing: the Association is being consulted by statutory training councils, by government departments, and by voluntary societies. It would not have been possible for this thriving Association, which covers all the countries of the British Isles, spanning more than 40 disciplines, ever to get off the ground without the benevolent neutrality offered by the King's Fund.

Assisting Change in the Management System

No opportunity has been lost to demonstrate the value of multidisciplinary management systems with a strong accent on participation and decentralization, and a good number of institutions have followed up the advice given in a project paper on the essentials of this approach. In addition, the project director has served on a public government enquiry into the management of a large mental illness hospital in the North of England and was thus able to have a considerable effect on the management of that type of institution. In a personal capacity the director was invited by management and unions alike to act as a one-man advisor on management/staff problems related to one of Britain's largest state security institutions for the mentally handicapped and his report is now being implemented.

The Outcome

It cannot be claimed that each and every activity listed has been fully successful, but looking back over four years of work it is worth trying to ascertain, although subjectively, what the result has been. Certainly the project has proved a focus for all disciplines and services connected with mental handicaps. Visitors from abroad testify to the breadth and independence of the project's approach. It provides a milieu in which contentious issues may be discussed in a neutral atmosphere. It has made it possible to give much direct help to hard-pressed mental handicap workers in the form of advice and tuition, mostly undertaken not by the Fund's staff but through the Fund's agency in enabling mental handicap workers to share their experience with one another, for it is they who have the practical knowledge. Over and above all this, it has proved a reliable and well-used sounding board for government purposes.

The Future

The project is scheduled to end in 1977, after a duration of seven years. The general policy of the Fund is to mount projects for a period of years and then to transfer these across to service organizations. A good example of this in recent times has been the development, after the American pattern, of the organization of hospital volunteers which, having been pioneered by the Fund, is now run by a separate organization, separately funded. The Fund's view is that if a project such as the mental handicap project were to stay with the Fund for too long, it would run the risk of becoming institutionalized. Rigid attitudes might develop and the project staff might gradually come to be associated with a particular point of view or be seen to take sides. In any case, a foundation like the King's Fund, whose resources though good are nevertheless limited, needs to be free to take up new topics and make new initiatives from time to time. In football terms, it might be said that the idea is to make a good run with the ball, to make a lot of ground and then pass. But the problem at the moment is, to whom should be ball be passed? To what sort of organization?

Here, the suggestion has arisen of some form of national multidisciplinary institute on the lines of some of the better institutes in the states of the USA. Here again is a topic which is of interest to the government departments concerned and may well interest a number of voluntary agencies. To start discussions on a topic of this nature will involve treading on such thorny ground as the nature of the professional input, the profession of the director, the general philosophy of its work, and so on. The informed neutrality of the King's Fund is bound to play a part here, as it will with other discussions currently taking place about the possibility of establishing a multidisciplinary national mental handicap executive.

The Role of the Foundation

It will thus be seen that the Fund has helped mental handicap, not just by giving money grants—for indeed, apart from the cost of project staff salaries, the grants made by the Fund during the period of the project have been relatively few. The main effect has been achieved by appointing a very small team, able to exploit the resources of the Fund for a limited period, with the object of handing over to a permanent body at a later date. The project has not sought to originate so much as to facilitate. Most of the necessary substances were already there, but they remained obstinately apart—they needed some catalytic agency to change them collectively into something quite different. This we hope has been the role of the Fund.

We would not presume from our one experience to attempt to lay down rules or procedures for other people in other countries, but certainly it would seem that one valuable instrument for change can be a foundation which has nothing to do with mental handicap, has no political power, no professional alignment, and no special axe to grind, but is willing for a specified period to put its resources into the impartial and disinterested service of mentally handicapped people.

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Biography

JAMES ELLIOTT is associate director of King's Fund Centre, London, England, where since 1970 he has directed a project designed to help improve services to the mentally handicapped. For many years previously, he was a health-care administrator in Britain's National Health Service. He edits the King's Fund quarterly, *Mental Handicap Bulletin*; he is the author of *Living in Hospital: The Social Needs of People in Long-Term Care* (1975); and is co-author with Kenneth Bayes, of *Room for Improvement: A Better Environment for the Mentally Handicapped* (1972).

Part IV: Patterns Which Are Changing

14. The Normalization Principle

Bengt Nirje

Institutions and services for mentally retarded people are changing, and so are prejudices and public attitudes. In the middle are the retarded persons themselves, with their handicaps and their awareness of being handicapped, and some of them are now taking their stand. They are on the move, just as countless young men and women are on the move all over the world. This move towards independence has a deep personal meaning for them, deeper than asserting the fact that they are adults.

In this context, I choose to see mental retardation as not one handicap but three. The question then is how we—the parents, society, and retarded people themselves—deal with these three handicaps. The three handicaps are:

1. *The mental retardation of the individual:* This means the cognitive handicap, the impairment in adaptive behavior, the learning difficulties, with the repeated demands imposed by new experiences and complexities, with the hurdles of frustrations and failures, with the problems of patience and of understanding others.

2. *The imposed or acquired retardation.* This is expressed in behavioral misfunctioning or underfunctioning due to possible deficiencies in the environment or the conditions of life created by society, or due to unsatisfactory attitudes of parents, personnel, or people in general. Institutional poverty, nonexistent or unsatisfactory education or vocational training, lack of experiences and social contacts, the problems of understanding society, etc., add to the original handicap.

3. *The awareness of being handicapped:* This is the insight into being mentally retarded, expressed in possibly distorted self-concepts or through defense mechanisms, closing in on inner sorrows, or defeated utterances. To assert yourself, in your own eyes or before your family and to confront society—friends, neighbors, co-workers or people in general—might be difficult for anyone, but the awareness of being handicapped brings a complicating factor—the problem of understanding oneself. And in the end, even the retarded person has to manage as a private person and has to define himself before others in the circumstances of his life and existence.

You might call these the three burdens of retarded people. The three handicaps are interdependent, but the second is openly available to cure: the burden of the handicap caused by social neglect or insufficiencies can be removed completely. This will not make the other two burdens disappear, but they will be easier to carry. The implications and demands of these three handicaps have to be carefully considered and respected in all facets of planning for retarded people.

The Normalization Principle

The normalization principle means making available to all mentally retarded People patterns of life and conditions of everyday living which are as close as possible to the regular circumstances and ways of life of society.

Normalization means sharing a normal rhythm of the day, with privacy, activities and mutual responsibilities; a normal rhythm of the week, with a home to live in, a school or work to go to, and leisure time with a modicum of social interaction; a normal rhythm of the year, with the changing modes and ways of life and of family and community customs as experienced in the different seasons of the year.

Normalization also means opportunity to undergo the normal developmental experiences of the life cycle: infanthood, with security and the respective steps of early childhood development; school age, with exploration and the increase of skills and experience; adolescence, with development towards adult life and options. As it is normal for a child to live at home, it is normal for adults to move away from home and establish independence and new relationships. Like everybody else, retarded people should experience the coming of adulthood and maturity through marked changes in the settings and circumstances of their lives.

Normalization also means that normal understanding and respect should be given to the silent wishes or expressed self-determination of retarded persons; that relationships between sexes should follow the regular patterns and variations of society; that the same basic economic patterns of life followed by others should apply also to retarded persons.

Finally, normalization also means that if retarded persons cannot or should not any longer live in their family or own home, the homes provided should be of normal size and situated in normal residential areas, being neither isolated nor larger than is consistent with regular mutually respectful or disinterested social interaction and integration.

Thus, the normalization principle rests on the understanding of how the normal rhythms, sequences and patterns of life in any cultural circumstances relate to the development, maturity and life of the handicapped, and on the understanding of how these patterns apply as indicators for development of proper human services.

This principle applies to all retarded people, whatever their degree of handicap and wherever they live. It is useful in every society, for all age groups, and can be adapted to social changes and individual developments. So it should serve as a guide for medical, educational, psychological, social, and political work in this field, and decisions and actions made according to the principle should turn out more often right than wrong.

The application of the normalization principle will not "make retarded people normal."* But it will make their life conditions as normal as possible, respecting the degrees and complications of the handicap, the training received and needed, and the social competence and maturity acquired and attainable. So the aims of care and services and the goals of training, in striving to develop a better adjustment to society, are also part of normalization. A realistic assessment of the degree of handicap, fluctuating social conditions and demands and the awareness that, for most people, independence and integration will be relative, are implied by the rubric "as close to normal as possible."

Superficially, the normalization principle might seem merely to apply to the life and circumstances of mildly handicapped people, or those not living in institutions. But it is wrong to think that living in the community can in itself be equated with being "integrated" into society. The question still remains of how closely the life of mentally retarded people approaches that of "normal" members of that community. In fact, the normalization principle will have its most far-reaching consequences for retarded people presently living in hospitals and institutions. Indeed, some of the ideas leading to its first development grew out of attempts to analyze the architecture, facilities, and programs of Scandinavian institutions for severely and moderately handicapped people, as well as some activities in special hospitals for those with profound and multiple handicaps.

What Does Normalization Mean in Practice?

Here are some implications for retarded adults on three general developmental levels, including consideration of the three handicaps outlined above.

Profoundly Retarded and Some Severely Retarded People

A living environment with single rooms allowing for privacy and a sense of personal dignity, intense care programs and social training, as well as occupational and industrial therapy training, work and leisure time activities including vacation time travel, have proved to help these people obtain a certain degree of independence in daily life. For those living in institutions, architectural planning in new directions for small special residences and hostels (group homes) is of utmost importance; for those living at home, the development of transport systems and occupation centers is a necessity.

The primary handicap will be diminished by adequate adult training; the secondary handicap will be replaced by new stimulation and motivation. As for the third handicap, at least the feeling of emptiness, the fears, and the risks to the mental health of retarded people will be considerably diminished. Scandinavian experiences have repeatedly shown that the change from bad wards to circumstances just described most often results in an outspoken new pleasure in life and a demonstrable strengthening of self-confidence and social adjustment.

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*They are, of course, as indicated above, basically as "normal" as you and I, though coping with handicaps. A person is a person first, the handicap is secondary. A child is a child first, secondarily blind or mentally retarded; an adult is first of all a man or woman in a social situation—as engineer, worker, sportsman—and only secondarily or thirdly paraplegic, deaf, retarded, etc.

Some Severely and Moderately Retarded People

Sustained occupational and vocational training, together with gradual social training and contacts with regular society, widens the life experiences of those living in institutions and those living with their parents. Special courses in home management and in living in training homes with a group of others are now preparing many to move out from institutions or from their families to small group homes. Indeed, with good vocational and social competence, some have been able to move on to share apartments with one, two or three others. In some rare instances, after counseling, couples are able to marry or live together as married, depending on the prevailing cultural patterns. Leisure-time training aims to help people use the resources of regular society and to obtain club facilities of their own.

The primary handicap will thus be assisted by adequate training and realistic motivation. The IQ has been shown not to be relevant to vocational or social capacity. As for the secondary handicap, new social approaches in planning and programs are needed, as well as a conscious and sustained dissemination of information to the general public. The third handicap is helped by a feeling of growing status and by a sense of security which develops from knowing you share the same pattern of life as other people.

Mildly Retarded People Who Have Left School

Special vocational education, vocational guidance, assessment, and placement services are essential rights. Social training and adult education, either in evening study circles or in longer sessions at special courses in regular "community colleges," provide richer experiences and a more steady background for meeting the demands of life.

These factors are also of importance for the more delicate and sensitive awareness of being mentally retarded. The young retarded adults often meet people who are unaware of the handicaps involved and who sometimes do not take particular care in dealing with others. Here we have the hidden frontier of integration, with the risks of casualties—depression, isolation, regression—especially when the job is not suitable or there is no job at all. For those living at home, the situation might be complicated by the specific stress from worries they feel and know their parents have because of them or sometimes from the revolt they cannot express against overprotection and underestimation. Adult education is of considerable importance here. One subject of interest for some retarded adults is psychology, which will allow them to discuss in groups and with the teacher their own experiences and their strife in obtaining a realistic concept of their limitations and abilities. Even among people defined as retarded, there are "intellectuals" (whatever that means).

The Components of the Normalization Principle

1. Normal Rhythm of the Day

Normalization means opportunities to have a normal rhythm of the day.

It means getting out of bed, getting dressed, and being involved in meaningful activities, even if you are profoundly handicapped and physically disabled. It means eating under normal circumstances, which also means sometimes outside regular meal times. It may mean eating in large groups, but mostly it will mean eating in a family setting, which implies rest, harmony, satisfaction, communication, communion and commotion. A normal daily rhythm also means neither going to bed earlier than younger sisters and brothers because of being handicapped nor going to bed very early because of lack of staff. The individual's need for a personal rhythm must be given consideration, which means opportunity to break away occasionally from the routine of his group.

To follow a normal rhythm of the day in units for profoundly and severely retarded people will mean restructuring facilities, programs, and activities as well as personal attitudes and tasks.

"When not being fussed over, he shrinks into a corner and thus disappears into the multitude of other patients in the dayroom." This extract from a report on a handicapped man illustrates vividly the passive monotony which is broken only by the unlocking of the dining room door when the mass of residents stream to the tables. Preserved food is quickly devoured, beverages in prefilled cups are gulped down, and then the whole group shuffles apathetically into the common toilets. Eating takes only a few minutes; toileting takes longer. Every adult is in bed at 5:30 p.m. so that floors can be cleaned during the last minutes of the daytime shift.

This daily scene indicates how imposed or acquired handicaps are fostered by routine life on the ward. Here the shrinking into a corner for hours on end is not an expression of a personal rhythm but a sign of loneliness and alienation. There is no encouragement to do something outside the rigid routine. The discipline enforced by that routine relegates everyone to the lowest common denominator.

Some men and women were moved from this sort of adult ward in a special hospital to an intensive care unit with single and two-bed rooms and small group sitting rooms, and offered proper training programs. The residents rise in the morning individually, depending on the time they need to wash and to dress before breakfast. They eat in small groups and can help themselves in comfort. They can use normally private toilets when they need to. In the evening they can watch television and go to bed when they wish. There are no locked doors in this intensive care unit, and the profoundly and severely retarded resident can break with the rhythm of his group when he so desires. In this setting a member of the staff can say, "Today Kent wants to skip class because he would like to train with the deodorants we bought yesterday instead." It takes some time to consolidate this training program but it pays excellent dividends to the residents and staff alike. To take just one example: for every 10 of the incontinent people in that special hospital given an intensive training program, savings would be obtained through five tons less clothing and linen to be washed and 600 staff working hours per year saved for positive work with the residents rather than for changing clothes and cleaning floors.

2. Normal Rhythm of the Week

The normalization principle also means opportunities to experience a normal weekly rhythm.

On the whole, people usually live in one place, work or attend school in another, and find their leisure time activities in a variety of settings. It seems, therefore, wrong that a retarded person should have his training classes, his special therapies and his recreational activities in the same building that serves as "home." The normalization principle underlines the fact that the three different sets of experiences—home, work, and leisure—cannot be satisfactorily expressed or experienced in an institutional setting.

The home is a personal area where you can be yourself and follow your individual or familial patterns of life; it is the place that offers privacy and security. The school or work situation, on the other hand, represents largely impersonal functions for cultural or social molding, offering assimilation of the cultural heritage or adjustment to social demands and values. Leisure time brings a mixture of personal and impersonal functions, offering opportunities for choice and self-expression as well as interrelations with, and adjustment to, others. For young people, leisure activities provide social learning and orientation, gradually widening horizons and increasing self-confidence. For adults, they offer social relationships, citizen participation and opportunities for deepening self-knowledge and maturity.

These basic facts of life must be taken into consideration in planning services, and this leads to the necessity of functional planning. Educational facilities—whether day nurseries, preschools, or classes for school age children which are as physically and functionally integrated into the regular community services as possible—should be planned not only for children living with their families but also for those who cannot and so need group or boarding or five-day-a-week homes. The same goes for sheltered workshops or day centers for adults: they should be accessible not only to those living at home but also to those who need to live in small group homes, training hostels, boarding homes, or service apartments. Leisure facilities should, in the same way, serve both those living in their family homes and those living away from them.

In this way, retarded people will be able to benefit from a normal rhythm of the week with increased options for social training. Functional planning of this kind will establish more realistic settings and better training opportunities and offer more support for development through an awareness of sharing more and more conditions of life with others in the community. Staff in residential services also get feedback from the neighborhood, which increases their own motivation and their professional status.

Functional planning starting with suitable locations of schools and workshops and subsequently arranging proper accommodations and recreational services, not only helps break up the institutions by providing more feasible alternatives but offers better options for parents with retarded children at home; their adult sons and daughters will be able to choose residential conditions closer to already familiar ones. Implementation of functional planning in the community offers the retarded persons, their parents, and society more options for their future development.

It is, therefore, imperative to separate residential and social services for children from those for adults. Boarding school life in a large institutional setting, where the children mostly learn about adult life by observing mass-managing staff or retarded adults, offers dangerously limited horizons and experiences. An additional danger is that the institution might impose a self-fulfilling prophesy by assuming that children will simply move to an adult unit when the time comes. In more and more countries now, parent organizations are active in fighting for the legal right of education for their children. This is not enough. Large institutions do not provide a proper pedagogical setting for the growing child.

3. Normal Rhythm of the Year

Normalization means experiencing the normal rhythm of the year by having holidays and observing family days of personal significance.

Most people take it for granted that they will change their way of living and refresh their bodies and minds at least once a year by going on vacation. In Scandinavia, travel, including travel abroad, has proved meaningful and valuable for even severely and profoundly handicapped people.

The present institution is a deviant environment, where the changes of the seasons cannot be experienced in the same full way as in normal society. The seasonal changes bring with them a variation in types of work, food, cultural events, sports, general leisure, and outdoor activities, but all this is more obvious outside the institution.

People live usually by routines and habits, occasionally by their wits. Poor children and mentally handicapped people have often to live by their wits, though the latter find it relatively more difficult to manage. Children explore and observe activities in the farm, the fields, the forests, the barns, the backyards, the stores, the market, unknown streets and neighborhoods, irrespective of, and because of, the changes of seasons. These are the teaching grounds which must also be used and explored by people living in institutions, but instead the institutions have provided an environment where distorted survival skills are sharpened. On the other hand, the author has come across records of profoundly and severely retarded persons which frequently noted self-destructive or aggressive behavior in wards, but without exception showed very positive reactions and behavior at all seasons of the year on visits to town or other excursions, when such regular programs had been introduced.

4. Normal Experiences of the Life Cycle

Normalization also means an opportunity to undergo the normal developmental experiences of the life cycle.

In the life cycle of parents of retarded children, there are two stages where the normal processes of life are broken or twisted. The first is when a child is born, or found to be, retarded; and the second is when the retarded child is growing into adulthood. Both these stages are of crucial importance to the parents and both also deeply affect the development of the retarded person, his start and his progress in life. This is why the most essential duties of a parent organization are concern for the well-being of young parents and of parents who are growing old.

Early Childhood

Normalization of the conditions of life for handicapped young children implies more than that all services should be geared to supporting families with retarded children from early on, with all that this means in terms of counseling, parent training, supportive services of different kinds and so on.

When a handicapped child is born, the main thing is that a child is born. The difficulties that may ensue are there to be understood and appropriately met. No medical practitioner should overburden the situation by forcing decisions of a wider scope than the mother can properly bear by advising separation of mother and child. We have known for quite some time how profoundly the mother's handling of the child during early development affects the child's intellectual and motor functioning and his opportunities for emotional and personal growth. It is, therefore, very important that parent organizations establish contacts with the medical profession that lead to better understanding among practitioners of the alternatives to institutional care available through services in the community, and an awareness of the ethical rules implied in advice to families on child development.

If later on, for any reason, a severely or multiply-handicapped small child cannot stay with his parents, and a foster home is not advantageous, the alternative group homes should be small and provide warmth and communication among the children and the staff. Something is utterly wrong in children's institutions when, for example, staff are rotated between dormitories every second day, with the express intention of preventing them from becoming attached to any one child.

The group homes should not simply provide adequate physical care. First of all, they should be homes for children; secondly, they should provide supportive developmental stimulation; and thirdly, they should have access to day nurseries and preschools in the community for regular child development programs.

If the child is physically handicapped and hampered in the experiences he could gain through regular motor development and exploration, he should be provided with physiotherapy and technical aids which increase mobility as well as further compensatory stimulation and experiences. If the child is blind, special efforts must be made to establish trust so that he will risk using his motor abilities and start exploring. Communication must be established with a deaf child as soon as possible through gestures, sign language, and so on. All these developmental supports, compensating for the additional handicaps, are necessary to prevent further retardation and emotional problems. The additional handicap must be considered first so that it does not limit the growth of the child more than is inevitable. Early developmental training, bringing the child as close to the normal developmental experiences and steps as possible, is essential, no matter where he or she lives.

These essential demands have proved almost impossible to realize in large heterogenous institutions which have shaped abnormal attitudes of staff and retarded adults. This sort of environment is completely unsuitable for the growth of handicapped children and is another compelling reason why children should not live in the same institution as handicapped adults.

School Age

Young people of school age in normal society live in a world partially structured for them. It is of basic importance to gradually learn about one's own personal abilities and potentialities, to acquire an understanding of oneself and to develop self-confidence. During this period, wide social experiences outside the classroom have important impact on the direction of development and the quality of personal stimulation. This also applies to handicapped youngsters and adolescents of school age. Mentally retarded school children and adolescents, therefore, should never live with retarded adults in a confined institutional setting which offers only a limited and distorted experience. The young people's impressions of life should be gained through contacts with normal society rather than a deviant society, and their socialization should be based on that of normal society.

When compulsory school attendance is extended to all children, including profoundly and severely retarded children, as is only right, the emphasis will be placed on the development of relevant educational programs. The question of housing for those who are now living in special institutions will be dealt with by doing away with the present children's wards instead of putting away the children. The new group homes will be small and designed specifically to meet the developmental needs of children. Thus educational and social integration can be acquired and utilized.

Adulthood

Growing from adolescence into adulthood is often a longer, more painful and more uncertain process for mentally retarded people than for others. Their self-image tends to be warped and confused. They are not always accepted, treated and respected as adults. Here, the attitude of others towards them is of the unmost importance, whether these others are parents, relatives or staff.

The time of growth of handicapped sons and daughters into adulthood represents the second stage in the life cycle of parents in which the normal processes and patterns are broken and twisted. This period is, therefore, bound to be of great concern to them as well as to retarded people. It is normal for children to live with their parents and it is normal for adults to move away from home and start a life of their own as independently as possible.

All services to mentally retarded people should be geared to this basic fact of life, by providing appropriate vocational or work training programs, training in boarding home living, adult education, widened social training, sex education, and so on. Like everybody else, retarded people should experience the coming of adulthood together with marked changes in the settings and circumstances of their lives. So mentally retarded adults should not live in the same facilities as children and youngsters because this would be a constant reminder that they are considered as dependent as children.

The aim of training programs for young adults should be to help them become as competent and independent as possible in their personal daily routine and to develop social skills which will enable them to take as much part as they can in normal community life. Such programs not only provide more realistic motivation but also meet the inclinations of the retarded people themselves. In this way, very important opportunities for training in decision-making can be offered and to make decisions is an essential part of maturing, becoming competent and experiencing dignity.

Programs of this kind not only help the retarded person, they also offer more constructive solutions to the problems of parents. In ordinary life, young adults move away from home, establish themselves, marry, have children, and are constantly redefining their relationship with their parents as the parents in turn become more dependent and finally die. Families with an adult handicapped son or daughter do not at the moment always experience this pattern. This causes stress to, and overprotection by, parents which in turn leads to stress in, and humiliation of, the retarded person. Worries about the future of the son or daughter are often intertwined with dreams of a perfect special residence that might suddenly appear to take care of the "problem"—dreams of "the final solution" which will make all the worries disappear.

These are burning and legitimate concerns which deeply affect the retarded person and his family. However, we should know by now that "final solutions" are hardly desirable in societies which offer development, participation, and constant change. Responsibility for the future of retarded people when their parents have died must reach beyond the limited horizon of the "final institution." Functional planning of comprehensive programs for retarded adults can bring the process of separation from parents closer to this normal pattern of life, and so support retarded people as well as their parents in redefining their relationship as other families in society do. In most societies, little consideration has been given to this normal process of life and so anxieties and despair are increased instead of lessened.

Old Age

The period of old age, when work is no longer possible, consists for most poeple of contacts with family or settings and acquaintances which have given life so much of its content and meaning. It should be possible for elderly retarded people to continue living in the place they know. If this is not possible, alternate living facilities for them should be close to where they have spent their adult life. Functional planning is as important for this stage of a retarded person's life as it is for the earlier ones.

5. Normal Respect

The normalization principle also means that the choices, wishes, and desires of retarded people have to be respected and always taken into consideration.

This includes paying attention to whose who do not speak or have difficult in expressing themselves. It implies due consideration of personal belongings; if possible, the retarded person should buy his own clothes and even furniture. Whenever possible, committees of retarded people should be formed and their representatives should take part in discussion with staff on rules, routines, and events.

As early as 1968, a conference was arranged in Sweden for 20 mentally handicapped young people, whose IQs ranged between 35 and 70, to discuss vacations and leisure time. They wanted a stronger voice in preparation of leisure programs, in student clubs, and in labor unions. They objected to being included in activities with children under 15 or 16 and to being in groups which were too large and too heterogeneous. They found communication difficult in large groups because it was more difficult to hear and to understand what was being said. They had obviously had too often the "tourist" experience of moving in herds.

At a national conference in 1970, 50 elected representatives went further into their experiences and points of view on residential and group home living, work opportunities, and leisure time interests, as well as their frustrations about having decisions made for them. Since then, regulations have been issued in both Denmark and Sweden which recognize the social duty to create relevant committees of retarded persons.

6. Living in a Heterosexual World

Normalization also means living in a heterosexual world.

Desegration of retarded boys and girls, men and women according to normal patterns of everyday society leads to a better atmosphere and results in better behavior because motivation for social learning is increased. Handicapped people sometimes suffer a senseless loneliness and it may be better for them to be married, like anyone else.

7. Normal Economic Standards

Normalization means applying normal economic standards as a prerequisite to enabling mentally retarded people to live as normally as possible.

Retarded people have an equal right to the financial help available to others through social legislation as well as to any other compensating economic security measures they may need. These include child allowances, personal pensions, old age allowances, and minimum wages. Although a larger part of these allowances will be used for board and lodging, individuals have the right to a normal proportion for their own personal use. This will assist realistic social training, help foster individual choice and increase their feeling of competence. Work in competitive employment, sheltered workshops, or within institutions should be paid according to its relative worth.

8. Normal Environmental Standards

The principle of normalization implies that standards for physical facilities like schools, work settings, group homes, and boarding houses should be modeled on those available in society for ordinary citizens.

This means that the scale of facilities should conform to the one applied in the open community. It is important to bear in mind that a residential facility for mentally retarded people should never be intended for a larger number of persons than the surrounding neighborhood would readily assimilate in its regular community life. When planning the location of residential facilities, they should never be placed in isolated settings merely because they are intended for retarded people. Normally scaled and located facilities will give their residents better opportunities to integrate successfully.

We might speculate on a formula for the relationship between size of space and time spent there. It seems reasonable to say that the larger the place the shorter the stay, and the longer the stay the smaller the place. Think of airports, stadiums, concert halls, regular hospitals, military barracks, colleges, apartment houses, family homes, the coffin—with due respect to the unfortunate and the enduring.

Large specialized institutions will become increasingly more uneconomical in time because of rising salaries and costs and growing political pressure from staff and particularly from the parents of retarded people for more humane approaches. Smaller residential homes can be easily sold or converted to use for other groups when demands or philosophies change. It may well be that the Western world could take a hint from experts in mental retardation in underdeveloped countries; they do not find large institutions economically feasible and they do not experience the same pressure from prejudice.

Physically disabled retarded people need a physical environment which provides the special technical features which will help mobility and social interaction. For instance, people who cannot use their arms should have special toilets with push button or lever operated warm water sprays and a warm air drying mechanism. Technical devices like this will make it possible for these people to be more independent and private.

Integration And People With Multiple Handicaps

Integration is a strengthening and enhancing process, which, by reason of offering more stimulation and dignity, should be applied as much as possible to support retarded people in their residential, educational, and leisure programs.

Just as a small group of mentally retarded people can easily be accepted in a larger social setting, a small number of moderately retarded people will benefit from integration into a larger group of mildly retarded people and a small number of severely retarded people can benefit from being integrated into a group which functions at a higher level.

The same pattern should be applied to people with additional handicaps. To help compensate for their handicaps, they should be integrated with people who do not have these handicaps and are functioning at a higher level, or if necessary with people with the same handicap who are not retarded.

But the same considerations apply here as apply to the small multiply-handicapped child: we have to start with the special handicap or we will make mistakes which can only frustrate the retarded person. There must be realistic planning for their needs, whether these should be met by architecture or through education and social training or in special adjustments to the working situation. Very often there is a superficial or false integration—we pretend the handicap is not there—e.g., when a deaf retarded person is placed in a ward for non-deaf retarded people: he is present but there is no communication. This is interpreted by the handicapped person as meaning that there is something unmentionable or indecent about his handicap, and this, in turn, frustrates his personality development.

By contrast, blind children today are offered special schools or classes where they can learn to use Braille and acquire the techniques which will increase their mobility and enable them to handle the environment. As soon as they are ready, they move to integrated schools or classes. The same applies to physically handicapped children who receive in special schools the training they need to enable them to move on. They have benefited from the group experience in acquiring competence to deal with their own special handicap and to take a certain pride in it. Thus, special needs and the quality of education offered might decide whether retarded children with an additional handicap should be integrated into classes for retarded children or be in classes for their special handicap.

Mentally retarded deaf people have often been sent to retardation institutions because they could not benefit from the lip-reading approach to education in schools for deaf children. They have, therefore, found themselves superficially integrated with retarded people with whom they cannot communicate and with a staff who do not have the skills to reach them. They tend to withdraw and become outsiders, even though, on the surface, they live an integrated life. Clearly, this situation endangers the development of their personality.

In Ontario we are now trying a new approach for adult deaf retarded people. Some of them have been brought from institutional wards into a special program where they are taught sign language and the skills for living in family houses and offered vocational and social training and compensatory adult education. As the first requirement is to establish communication with them, half the staff are themselves deaf, bringing all their experience of the difficulties of acquiring language and of coping with the hearing environment. The hearing staff are also trained in sign language and thus an environment has been created in which sign language is a significant part of total communication.

The program has shown that it is possible to create enough language and communication skills among deaf retarded people to enable them to receive the further training they need. These people have acquired a new image of themselves, and their potential to cope with a hearing world has increased. Some of the participants might be integrated into the deaf community, which, in its turn, is integrated into the normal hearing community. Thus, through applying the principle of normalization and offering these people conditions of life which are as normal as possible,they have been brought to wide opportunities of integration, although remaining deaf and retarded, they have become more and more themselves.

Some Implications of the Normalization Principle

Through application of the aspects of the normalization principle, as outlined, many mentally retarded people can be helped to achieve complete independence and social integration. A great number can be helped to develop considerable independence, even though they may always need various kinds of support. Even the relatively few people who are severely or profoundly retarded, or those with complicating medical, psychological or social handicaps will, by following the principle of normalization, have their chance to live in and respond to conditions, facilities, and services which follow the normal patterns of society. Nevertheless they will achieve a growth in independence and personal fulfillment in a sheltered environment which is far greater than many of them are offered today—and to which they, no less than anyone else, have a right.

The closer the decision-making bodies of society come to understanding retarded people's needs, the more likely they will be to develop appropriate and effective programs. The normalization principle does not just affect the lives of retarded people, it has a deep effect on those who work with them, their parents and society itself.

Residential facilities for mentally retarded children must be seen as homes for children; special schools must be integrated with regular schools and seen simply as schools; group homes and hostels for mentally retarded adults must be seen simply as homes for adults. Only then will society's attitude towards mentally retarded people become supportive to normalization. Isolation and segregation nourish public ignorance and prejudice, while integration and normalization of the ways of life of smaller groups of mentally retarded people provide the opportunity for the ordinary human relationships which are at the basis of understanding and social acceptance and integration of the individual.

A normalized setting will also help the staff who work with mentally retarded people. They will appear as social educators, helping to encourage independence, rather than as custodians. They will enjoy a higher status, which will increase their self-respect and their effectiveness.

Finally, the use of the principle of normalization can help parents. When residential homes and schools of normal standards, scale, and location are available, as well as day centers and workshops, the parents of retarded people can choose according to the needs of the individually handicapped person and of the family. Choice of placement will be made more freely and with an easier mind instead of being an anguished decision between the horrible and the impossible.

Biography

BENGT NIRJE was born in 1924. He received his undergraduate training at the University of Uppsala and the University of Stockholm, obtaining a B.A. in comparative literature. From 1952 to 1954, he did graduate work at Yale University on a Smith-Mundt Bill Scholarship and at the Sorbonne in Paris. From 1956 to 1958, he worked as a welfare officer on the Hungarian refugee problem, first for the Swedish Red Cross in Austria and later for the United Nations. In 1958–59, he was in charge of the organization of the Folke Bernadotte drive for cerebral palsy. From 1961 to 1971, he was executive director of the Swedish Parents' Association for Mentally Retarded Children. In this capacity, he functioned as an "ombudsman." Since 1971, he has been working for the Government of Ontario and is presently a consultant in mental retardation program development in the Community Service Development Branch in the Ministry of Community and Social Services, Ontario.

15. Denmark

N. E. Bank-Mikkelsen

Historical Development

Denmark is a small country of 16,600 square miles with an evenly distributed population of 5 million, a well-developed communications system, and a relatively even distribution of social, medical, and educational services within easy reach of the citizens. The social security systems are of such a quality that Denmark must be regarded as one of the "welfare states;" it considers itself as such. This has created a public expectation of equality—in education and in situations of disease, accident, and death.

Nevertheless, losers do appear even in a system like this. The mentally retarded are among those deviant groups which have turned out losers because they are a minority and minorities are constantly singled out, mainly in a negative way. This negative discrimination is seen in the fact that they do not achieve the equality which is considered a basis of a well-developed democracy.

A detailed analysis of the past may prove that we have gone through the various stages so well described by Wolf Wolfensberger in our own development. This paper is not intended to be such a thorough analysis but merely an illustration of this development.

From "Belief in Cure" to Protectionism

The first institution for the mentally retarded was established in 1855 on a private initiative; this was a small school home with 24 places. The inspiration came from Switzerland and the rather optimistic objective was to cure mental retardation—to make "normally gifted" persons out of the pupils. The means were both medical and pedagogical, and a substantial part of the education consisted of physical training. After a few years, the project was abandoned. No one was cured and from then on the objective became custodial care, characterized by a protectionism which aimed at protecting the mentally retarded from society, and even society from the mentally retarded. The overall protectionist attitude was reinforced by the theory held at the University of Copenhagen almost up to World War II that there were groups of mentally retarded people who were dangerous, criminal, unstable, and so on, as a result of their mental retardation.

This protectionist philosophy led to the isolation of the mentally retarded in special institutions which were often beautifully sited but were also remote. Larger and larger institutions were then established to soften the isolation and create a more varied small society; these catered for all types and degrees of mentally retarded people. So societies of the mentally retarded were created and the aim was to make these societies self-supporting.

As early as 1888, however, a few mentally retarded people were placed in so-called "family care," chiefly with farmers where the most able men could participate in simple work and the women in domestic tasks.

From the beginning of this century, the diagnosis of mental retardation was exclusively determined by an IQ test, and the upper limit set at an IQ of seventy-five. People believed in the "permanence of IQs"—a theory which is today completely abandoned.

Residential Care—Led by Physicians

The objective was to take care of the clients without any real treatment—they should live a nice, cozy life. Schools were gradually established at the larger institutions for the education of the most able children—the "borderline" and the mildly retarded. This education was adapted from normal education and distinguished clearly between the "educable" and the "noneducable;" the latter had no right to education. Apart from a single private school, there were no day schools for retarded children until after World War II. As the ordinary primary schools refused to give education to the mentally retarded, parents had no alternative to sending their children to a residential facility; only a minority of them did so.

The large institutions were led by physicians as administrators. By the 1930s, psychiatrists had begun to show interest in services for the mentally retarded. This led to better examination and diagnosis and some improvement in the hygiene of the institutions; this was the hospital model. There was no systematic pedagogical or psychological work except for the small boarding schools mentioned above.

Until World War II, Denmark met the demand for institutional places better than any other Scandinavian country; its coverage was maybe even the best in the world. The quality of care was also described as somewhere near the best in the world. These are, of course, very relative judgments.

The housing conditions, serving as they did an isolated minority group, were obviously poor; they were, nevertheless, satisfactory, given the objectives of care. It should not be forgotten that legislation and practice made it possible to empty the jails of all mentally retarded people; they were then condemned to residence in institutions for the mentally retarded. Some of these institutions had, and still do have, special closed wards for the so-called "criminals."

World War II and the Post-War Era

World War II put an end to the further expansion of large-scale institutions but, unfortunately, this started again before the new approaches had broken through in the 1950s. Large wards with dormitories of as many as eight beds were built in Denmark as late as the early 1950s. Small institutions with between 20 and 40 places had been built during the war, of which most were privately owned and publicly supported. But these small homes were considered temporary solutions which went against the institutional philosophy.

This description is necessary if we are to understand the huge problems facing a new philosophy. We had a relatively well-developed system, fully financed by the public, essentially medically-directed and, apart from certain quantitive lacks, considered satisfactory by most of the professionals.

These quantitive lacks were chiefly in housing, which led to a demand for more wards and still larger institutions. In the occupational field, it was recognized that clients would participate in the work of the institution—in the gardens, the kitchen, or in cleaning work. They would have leisure activities like handicrafts, needlework, and weaving but there was no industrial work and there were no sheltered workshops. Some of the professional leaders considered that the mentally retarded had the right not to work, simply to vegetate.

Growth of Criticism

The quantitive gaps in this state-supported system meant overcrowding and waiting lists. On the whole, even professionals who were otherwise generally content with services agreed that these gaps existed. The central health authorities had also criticized standards. Professional criticism began among some teachers, psychologists, and social workers, but the real and harsh criticism of the established system and its objectives came from the growing Association of Parents.

A National Association of Parents had been established in 1951–52. Only a few professionals understood this development and they joined the Association's work. Most were skeptical and considered the Association a quarrelsome group which should not have any influence on their work.

In December 1953, the Association sent a note to the Minister of Social Affairs, who was responsible for services, requesting the appointment of a committee to discuss the problems of these services. Among other things, the Association set out the following solutions to current problems:

- residential facilities, as mentioned above
- the establishment of small institutions with between 20 and 30 beds near parents and relatives
- better supervision of and more general and financial aid to clients in the care of others
- education and training for clients and general compulsory education for the all educable children, if necessary over a longer period than other chilren (the right to education)
- better legal protection, including juridical control of all those involuntarily placed in institutions
- guardianship arrangements
- the right to complain
- the principle of voluntary services
- day care facilities for adults as well as children, including special workshops (the concept of sheltered workshops was not known in Denmark in this field at this time)
- liaison committees for the institutions, including representatives of junior staff and parents

Finally, the Association stressed the need for greater educational and psychological influences on the service.

Some four months after this note, the Minister for Social Affairs set up a committee which included two parents' representatives. It reported in September 1958, and the following year many of the Association's wishes were met in a new Act.

Clearly, the Association was the immediate and most powerful reason for the review of the Danish Service for the Mentally Retarded at that time; it is also because of the Association that reform was given the right objectives. Reform was difficult. On the one hand, a system which the experts in principle considered satisfactory had to be broken down; and on the other, a completely different system had to be built up.

Some Reasons for Change

The attitude of the Asssociation of Parents was new. It created the possibility of an open discussion of the problems and also led to an acceptance of the problems throughout society. It thus created political support for reform.

The new parental attitude was based on certain facts. These included new knowledge about mental retardation, especially about its etiology. It was now evident that this was not a social problem limited to the lower social group. Every family had to consider the risk of having a mentally retarded child. This somewhat reduced the feeling of guilt and shame which surrounded the subject. The open discussion also revealed that many of the institutionalized mentally retarded, even the majority, were living in conditions which were unacceptable to a country so proud of its relatively high social standards. New knowledge on treatment (medical, pedagogical, psyschological, and sociopedagogical) had eventually to lead to demands for active treament—for example, education.

From Protectionism to Normalization

The theory of mental retardation as a static and lifelong conditions went well with the practice of "putting away." The new knowledge that mental retardation is a dynamic condition which can be influenced by treatment, education, and training meant a new objective for services. The 1959 Act expressed this as "to create an existence for the mentally retarded as close to normal living conditions as possible." This phrase was the basis of the theory later to be called "normalization" which was, and still is, a challenge to us in our country and to many in other countries where a new attitude towards handicapped people has been created.

There have been semantic problems about the very word "normalization." Some have misinterpreted it to mean converting mentally retarded people into so-called "normals." Normalization does not mean normality. A mentally retarded person is not normal—who is? What is normality, and does anyone want to be "normal" at a time when there is so much understanding for people who are trying not to be uniform? Normalization means making normal mentally retarded people's housing, education, working, and leisure conditions. It means bringing them the legal and human rights of all other citizens.

Normalization is basically an attack on the various dogmas, especially protectionism, which have for centuries worred mentally retarded people. Normalization is an antidogma. It means that mentally retarded people should not be treated in any special way. A logical conclusion of the concept would be to deny the existence of a special group of people called "mentally retarded." In the near future, Denmark will show that no special service is needed to take care of the mentally retarded. We hope that the philosophy will become strong enough to eliminate distinctions between the normals, the mentally retarded, and other deviants. This, of course, does not mean that mentally retarded and other handicapped people do not have a right to special education or special treatment. But this should be provided according to need and not merely because they are mentally handicapped and the same should apply to other citizens who need special provision for a short period of time or for their whole lives.

Integration and Segregation

Normalization has often been confused with the problem of integration and segregation. It should be stressed that, while normalization is the objective, integration and segregation are simply working methods. They are means which can be selected according to the evaluation in each situation of what would be the most suitable or efficient way to reach the goal. We know from experience that segregation is not usually the best means to achieve normalization. But to my knowledge there is no unambiguous evidence or documentation to show that segregation of severely and profoundly retarded people in special schools or special classes would not work as effectively towards normalization as integrating them into normal classes. This is just one example to highlight the often rather superficial discussion on integration.

A distinction needs to be made between integration in housing, work, education, and so on, and integration for individuals or groups. Everybody who know the problems of profoundly retarded people may agree that ingegration is neither the aim nor the only means; everybody, however, agrees that normalization should be made available to even profoundly retarded citizens.

We return to the Danish Act of 1959 whose purpose was "to create an existence for the mentally retarded as close to normal living conditions as possible." This rather simple formulation was the starting point of the whole international discussion about the concept of normalization. We can be rather anxious about all the theorizing which has grown up as it seems to lead away from the original idea. This is that no specific theory should be applied to the objectives of work with and for the mentally retarded; that these are ordinary people who must have rights and duties similar to those of every other citizen. So normalization is set against the theory of protection or overprotection. It operates in terms of equality. It is part of the struggle for civil and human rights for every person.

Inequality has expressed itself most strongly in the Third Reich, where treating certain groups differently, because of race, religion, or handicap, had led to the elimination of these groups. This is unacceptable, and the only way to avoid a simlar discrimination in the future is wholly and fully to accept all human beings as equal citizens no matter how they were born or how they turn out to be.

Equality Under the Law

A significant element of the normalization theory is thus the juridical and administrative view that all are equal under the law.

To illustrate this, it is worth mentioning that to ratify a convention on human and civil rights passed by the European Council on November 4, 1950, Denmark was forced to change various statues. These included those covering the commitment and detention of mentally retarded people. The country's Constitution was itself being changed at the same time; as a result, the Constitution now contains a guarantee that commitments made by the administrative authorities can be challenged in the ordinary courts of the country.

Under very restrictive legislation passed in the 1930s, mentally retarded persons could be detained in institutions against their will if they would be of considerable nuisance to society, if they were incapable of supporting themselves, or if there was an obvious risk of their having children. In the last case, release would be conditional on sterlization beforehand.

These far-reaching regulations were a result of the theories of the 1930s which were racially motivated and aimed to isolate all deviant persons in institutions. The objective at that time was to have all mentally retarded people registered, institutionalized, and only released when they had been sterlized. Available eugenic knowledge had led to the belief that this was the way to abolish mental retardation. It will not be necessary, with today's knowledge, to explain why this did not succeed and why it turned out to be impossible even to reduce the number of mentally retarded persons by this method.

Juridical Control

In 1954, as we have seen, all administrative detentions could be brought under juridical control. In 1959, the restrictive legislation was further amended so that today it is possible to detain only those mentally retarded people who are considered dangerous to themselves or others or who may, after release, be a considerable nuisance to themselves. Even these decisions may soon be brought under control of the courts and we hope that there will soon be equality between mentally retarded citizens and others even here. This is normalization. Legislation on sterlization has already been passed; it is now voluntary for all citizens, including the mentally retarded.

There was much discussion of these restrictive rules during the 1950s. Psychiatrists were criticzed for detaining clients for far too long and for no obvious reason. The service today is based almost entirely on the principle of a voluntary use of services.

Attitudes Toward Developments

Administrative lawyers inside the Danish central administration took a major part in discussions about legal protection. While most of the professionals in the institutions did not understand the views of the National Association of Parents, these were immediately accepted by the Ministry of Social Affairs, which had recognized the Association only a year after it started and had brought two representatives of it onto its consultative board.

A few administrators with various professional views were from the very start of the Association working closely with the parents. The psychiatrists were generally very conservative, defending the established system where they had power. Teachers had a rather limited influence but were to become significant when the 1959 Act was put into effect, along with the relatively few social workers in this field.

A large number of care personnel were very cautious about change, but after the Act made reasonable demands for a better education. The administration of the Board of Mental Retardation and the Ministry of Social Affairs agreed to this. A special course was set up in 1961 which lasted for three years and produced qualified "care assistants." This improved education attracted so many applicants that it has ever since proved impossible to accept more than about half of those qualified to take the course. This increased demand for places has thus meant an increased quality as well as quantity of care assistants.

As already mentioned, the establishment of the Parents' Association had led to public debate which both critized the existing system and demanded a reformed service. This, in turn, led to increased opposition among the majority of professionals. Even before the 1959 Act, however, the administrative board of the service had had a positive attitude towards public relations. When the Act established a single national system with an executive board, including two representatives of the parents, the line was very clear: openness and frankness in every way.

There was no concrete, formal public relations activity. But the positive and frank attitude of the board turned the news media's considerable interest to its own account. Any reporter coming up with questions would get the best possible answer from the head office. If he wanted to visit institutions, this would be arranged. The doors were opened wide. Press, radio, and television were free to write and photograph whatever they wished. All they had to respect was any individual client's wish not to be photographed.

I remember one visit by a very prominent guest from the USA. He did not object to a crowd of photographers who followed us all over the institution but he was horrified as, in a most natural way, they followed us into a physiotheraphy area, still taking pictures. When he asked if this was allowed, I was able to answer that we had nothing to hide and that, furthermore, our work was carried out with taxpayers' money and that we had a responsibility to them; and, yet, that we protected the integrity of those who did not wish to be photographed.

We have also sometimes invited the press and television to photograph unjusitifiable or unacceptable conditions. In our monthly journal we have published similar pictures and have described our needs in order to create acceptance of our requests for financial grants. We have, over a period of years, made public our "black spots"—dormitories with too many beds, for instance—to put pressure on those who are financially responsible and to create understanding among the public that it is reasonable to use public money for these purposes. We have made public the number of children who do not yet receive a complete and systematic education, even though they have a specific right to this.

Ever since 1961, we have sent out a monthly journal to the entire staff, with articles on the service's work, including criticism of the rate of development. Between 1960 and 1970, we arranged an annual assembly of about 300 members of the service's staff, who represented every category and rank, during which we presented the results of the previous year's activities and compared these with development in other social and health fields. The press, radio, and television of the entire Kingdom were invited and almost every year this had a positive effect; the public news media wrote a lot about mentally retarded people and the service. This would often mean criticism of the politicians who, despite their own positive attitude, did not quite live up to our expectations and demands. Naturally, these assemblies were not popular in some circles and we very much regret that they do not take place any more.

A critical attitude among consumers, the public, and ourselves as those responsible for services, is only part of the public relations activity. It is equally important to describe how it is possible to obtain positive results by making resources available. This proves relatively easy in this sort of area; we have experienced great public understanding of work for the handicapped. Setting priorities in distributing public funds is a difficult political task, but this country, once provided with good information, has shown a positive attitude.

A general problem seems to be "not in our street." People may accept community services but still feel that a hostel, day-care establishment, or any other institution should not be opened where they themselves live. In nearly all of these cases the news media has taken the side of the mentally retarded against the local protestors. All we have to do is to tell the press that a protest is coming up and they will organize the rest themselves. As the result of 10 to 15 years of public information, we have succeeded in bringing the news media onto our side, to the advantage of the mentally retarded.

During the last few years, this has also led to rough criticism of the responsibile administrative board—the board which I represent. This is a natural development; it is also rather uncomfortable and we may feel it to be a bit unjust. The main line of criticism is that we have not yet put all our fine theories into action. The ideas which were once presented by the service itself have become public property and the public now demands action on them without understanding the complicated balances of responsibility between legislators and administrators.

Fifteen or twenty years ago, the consumers, including their parents, were an oppressed group with modest desires, grateful for anything which would bring progress. Today, fortunately, they are free and sovereign persons or groups, claiming rights which have been promised by the politicians and not yet realized in full. All this is part of a positive development, a kind of normalization.

Factors Which Have Been Unimportant in Denmark

Let us look at some factors which have been important in other countries but practically without significance in Denmark.

1. Voluntary activity has had no significance apart from sporadic initiatives from the Association of Parents and from various scout-groups. The Parents Association works chiefly as a pressure group and a very important one. It does not run facilities but it owns a number of institutions which it rents to the State which pays all operational costs.

2. There have been a few well-known Danes who, speaking as parents, have helped to create an acceptance of the fact that mental retardation can "befall" anyone. But we had neither a John F. Kennedy who did attack the problem nor a Charles de Gaulle who did nothing in particular about it.

3. The church has never played any significant part in work with the mentally retarded although it has been very active in other social fields. This may be due to a confidence in the welfare state: it will do whatever has to be done. A misplaced sense of security!

4. The universities took hardly any interest in anything except sophisticated research without great practical value for the daily work for our clients. Research in mental retardation has been encouraged by the service itself. It has even given financial support to research within universities out of its current budgets.

5. The courts have had a reasonable significance through cases of administrative detention, especially in the 1950s and recently, by limiting the number of people sentenced to live at an institution for the mentally retarded. Otherwise, the courts have played no role.

Some Areas of Controversy

Until 1959, the administrative responsibility for all services within each region—all institutions, community services and private accommodation—lay with the psychiatrists. This system was then completely changed into one with a multidisciplinary leadership made up of a chief physician, a director of education, and a director of social work; they are now, with the business administrator, responsible for all services.

This shift in responsibilities was heavily criticized, especially by the physicians. There were problems of "generation gap" but as time went on almost all the leaders of the service were in favor of this sort of teamwork. This structure, which has led to some effective results of treatment, might now be somewhat altered.

Everybody, however, acknowledges that the mental retardation service is a multidisciplinary work which should include at least the disciplines already mentioned and, in addition, representatives of the care assistants, who now receive three years' special training. A recent educational reform means that this training will now become general for the whole field of social work; it provides chances of greater specialization in work with children, young people and the elderly rather than in work with categories of handicap.

The special categories of blind, deaf, physically and mentally handicapped, and so on, will disappear from the administrative and legislative system. This is normalization; equality with other citizens without categorizing groups. This will be accompanied by administrative normalization; the responsibility for all these citizens will be handed over from special administrations to the local authorities in counties and municipalities.

This complex of problems is only of interest in countries where special services for the mentally retarded have been developed. Developing countries, which are starting from scratch, can avoid these developmental stages through which many Western countries have had to pass. (See also my paper: *Ideology and Practice in Labelling and Registration*, Montreal, ILSMH, 1972.)

Normalization itself had been controversial in Denmark. As argued above, normalization is the very opposite of protectionism and we still have many sympathizers of protectionism in our country. This attitude still persists among our personnel as well as in large segments of the population; partly, at least, because of lack of knowledge, these people maintain the old, protective views of the mentally retarded. This is particularly true among the older generation of parents who can hardly understand that when their children grow up they should live away from the family home and so be freed from the usually overprotective attitude of their parents.

In Denmark we have not theorized so much as in other countries about normalization. And yet we have often misunderstood each other, with or without cause. The concept has been controversial in Denmark, just as it has elsewhere, but remains one of the most positive challenges in this field.

Mixed Sexes and Sexual Life, Marriage and Children

The problems around the two sexes have naturally been controversial. The Danish population is known to have liberal attitudes towards sexual problems, so discussions have probably been more relaxed than in other countries. We have, however, to realize that prevailing prejudices in this field have been magnified when it is mentally retarded people who are under discussion. We have no special religious prejudices; the Danish National Church (Evangelical Lutheran) has a liberal attitude and our very few Catholics are comparatively liberal in this respect.

Mixing men and women clients in institutions and wards has been generally accepted, the speed varying with the tradition and outlook of individuals. Much of our old housing is built in such a way that it cannot take people of both sexes, whether they are mentally handicapped, have other handicaps, or are not handicapped at all. This has been because, for example, we still have a few dormitories of almost twenty beds with common washing and toilet facilities.

New wards, hostels and so on are planned to take both sexes. These houses take it as a human right that their inhabitants, at least the adults, should have single rooms. This principle has been much discussed and, unfortunately, is not yet in force everywhere. Mixed children's wards have never presented any problem; they have existed for decades.

The right to sexuality is a fundamental human right but a right which mentally retarded people have been deprived of in most parts of the world. Denmark has, in principle, accepted this right for the mentally retarded, but there are still great problems about procedure and there is a long way to go before the principle is accepted by everybody. Mentally retarded people receive sex education at school and at home, like everybody else. This does, however, create problems, especially for the personnel. We have discussed these problems in public—for example, whether staff should teach severely and profoundly retarded people to masturbate if this is their only sexual release. Opinions differ on this but the meeting showed that discussion of sexual problems is at quite an advanced level. Old protectionist views were put forward as well as fears about exploitation and abuse of retarded people. But attitudes were, on the whole, positive. After a three-day public meeting on this subject in the sixties, development started quitely and in the right direction. Prejudice, however, means that there is still a long way to go.

Danish legislation requires mentally retarded and mentally ill people to get special permission for marriage. This Act dates back to 1922 and was extended in 1938 to include even the mildly retarded; it was largely motivated by eugenic considerations. A recent government commission has recommended equality between mentally retarded and other citizens here; its report will be approved by Parliament in the contest of a wider liberal reform of Danish legislation on marriage. Many mentally retarded people who ask for permission to marry already get it. They are mainly mildly and moderately retarded; severely and profoundly retarded people seldom wish to marry.

The need for mentally retarded people to ask special permission to marry has been one of the points of discrimination which the Board of the Mental Retardation Service, as well as the Parents' Association, would very much like to see changed. Equality in this field has been largely accepted in Parliament and throughout society although the old protectionists have protested. It seems quite paradoxical that they should wish to protect the mentally retarded even against something generally accepted as happy, fine and beautiful. But then these "isms" can lead in some strange directions.

The question of children has been tied up with discussion of the right to marry. These are, however, two quite different problems even though, statistically, most children are born within marriages. Whether a mentally retarded or other other citizen should have children must depend on a judgement of each case, on economic, social and human grounds. Some mentally retarded people will be able to have children—others will not. This is also true for the rest of the population. The question is simply one of giving good advice in family planning. The question of contraception is easily solved today and there can be no doubt at all that mentally retarded people have a right to the pill and to other contraceptives.

We all know that debates about mentally retarded people's right to marry are most often hyprocritically hidden discussions about their right to a sexual life. It is my experience, from discussions all over the world, that understanding of the mentally retarded person's right to normal living conditions often gives out when it is a question of their sexual life, raised under the cloak of marriage.

Some Political Considerations

The period after World War II, especially between the mid 1950s and the end of the 1970s, was marked by a rapid and positive development of our services for the mentally retarded. One of the main reasons behind this development, perhaps in the end one of the most important, was the fact that Denmark could afford at this time to spend much more money on the handicapped than every before. We could afford a new attitude. We made the most of this period and at least went so far as to start the development of a new attitude among the general population. This is crucially important and cannot now be reversed, whatever else happens. There have, however, been recent political changes. Protest movements, borne along on resentment at taxation levels and the desire to reduce government expenditure, have gained influence. Even if such movements have only a limited political power, they are, nevertheless, symptomatic of a changed attitude in society and indirectly they push the attitudes of other political parties in a reactionary direction.

A politically reactionary attitude brings dangers to a state-supported system like the Danish one. The entire mental retardation expenditure is collected into an annual budget at central government level, easy to discover, easy to lay hands on, and easy to reduce. We have already found that purely fiscal considerations have restricted our resources. In the past, these have mostly slowed down our rate of growth but in the future we may expect restrictions which hit our services more directly.

The decentralization of the services, which is expected to be complete by the end of the 1970s with responsibility given to local authorities, may reduce the risk of reducing the central budget. A decentralized system, however, implies other risks—heterogenous services in different parts of the country, for example. This is against the principle of equality which is basic to normalization.

Privately-financed services in mental retardation are unknown in Denmark. However, the harsh economic conditions which Denmark and other Western countries are likely to meet in future may well lead to private initiatives. Paradoxically enough, these economic difficulties are the result not of proverty but rather of wealth.

These dangers, which will arise in countries with developed service systems, should probably be fought with the weapon we use in the fight to improve unsatisfactory systems. The most important of these is the spread of information—public relations activities.

Clearly, the Parents' Association uses public relations as an important tool. This will often, however, be taken as subjective pressure from discontented consumers and so should be backed with more objective material from the professionals. We have found in this country that consumers' views and professional evaluations are, as a rule, identical. Public relations activity is of paramount importance. It should consist of descriptions of gaps and insufficiencies in services and of information about the possibilities of improving standards. In certain situations, it can use cost-benefit considerations; this is politically efficent but it should go further and argue from a human standpoint.

In the past, politicians and the public regarded progress in the field of mental retardation and a reasonable improvement in conditions of living, working and education as a matter of course. Today, they focus the debate in two ways: how are the resources being used and what are the economic and political consequences of the current policy?

Evaluation is the necessary and natural demand. This is true of all resources—money, housing, personnel, and knowledge. The most important of these is personnel, which swallows up three-quarters of the total expenditure. Do we get the optimum benefit from their efforts? How is the personnel composed? What is the level of cooperation between different groups? These are all banal problems in the utilization of rescources but are seldom seen in relation to the objective.

Work descriptions are an essential byproduct of resource investigations. They are useful in making comparisons with service levels in the fields. Is the scope of the eduction offered to the mentally retarded the same as that offered to the so-called normal child or to students in our universities, for instance? Comparisons can also be made between housing conditions for the retarded and for other citizens. Resource investigations, which are often based on the politicians' desire to limit resources, may lead to information which could result in decisions to supply new resources.

Politicians naturally also want to find out what are going to be the consequences of what is being done in the here and now. It is also necessary to see whether the stated goal has been reached. This is part of a planning process, a modern political method, which can be used positively or negatively. Planning can be used to slow down or even to stop progress.

Demands for additional information to improve the planning procedure in the long term may bring a slowing down in meeting urgent needs which demand no debate. Skillfully used, however, planning procedures can stimulate development and are always a way of adjusting the input to reach the objective.

These considerations are merely popular views on the use of resources and planning. They simply describe modern administrative working methods which are necessary and important tools of progress. Evaluation and planning are obviously important in Denmark today; their use in political circles seems to be to slow down the rate of development. They may result in a better use of resources; they may also reveal the need for further resources even if the existing ones are used in the best possible way.

The current critical political attitude should be seen as part of a greater whole. The Danish welfare system started in a period of poverty of different levels. Poverty, in the sense of a deprivation of food, clothing and housing is almost unknown in today's society. In general, Danish citizens, in spite of current economic problems, have only minor financial difficulties, although it must be stressed that there are still individual cases of poverty which no government has been able to eradicate. On the whole, however, we have passed the epoch where legislation is aimed to provide survival conditions for the individual and his family. Today's problems are those of distributing financial and other resources and, in this situation, it might be wise to reconsider priorities.

The mentally retarded will certainly then still turn out to be last in the queue. It is my personal view that some groups of handicapped people belong to the nonfavored and that, in spite of all the progress, the mentally retarded, not as much in general but still as individuals, are among those who get the lowest priority. Foreigners from other countries have described the Danish service for the mentally retarded in the most positive way possible. We acknowledge that much has happened in the last 15 to 20 years. Nevertheless, as the Parents' Association has said, our services must still be considered as a kind of "developing area."

Let me finally revert to the crucially important question of attitudes. The most important and primary goal must be the creation of positive attitudes towards handicapped people. Just one crude example will illustrate how much still remains to be done. There are many severely and profoundly retarded children who receive no education. If a "normal" child refused to go to school when he should, his parents would be forced to send him. If they refused, the child welfare authorities or the police would intervene.

So does society accept that mentally retarded children should receive no education? The only protests when they do not go to school come from parents and professionals in the field; as minority groups, they will often be disregarded. Clearly, full equality has not yet been achieved for the handicapped.

Attitudes have changed over time. They have changed among parents, among the mentally retarded themselves, among professionals working in the field, and, to an increasing extent, among the general public. The most crucial point now is the attitude of the politicians. Our knowledge and experience is, after all, far ahead of what today's financial resources enable us to do. We are prepared to do whatever the legislators want of us for our mentally retarded citizens.

The Tale of Statistics

This concluding passage provides a numerical illustration of some of the views stated above. Table I offers a documentations of the development in the number of facilities and their size since the existing system was established in 1948-59.

These statistics show an evident development in services towards a system of smaller residential units for those with need for housing. On the other hand, there has been a definite increase in the number of clients at extramural facilities—schools, kindergartens, and workshops—and of clients who can live totally or partly in their own flats, in a room, in hostels, or with their parents.

TABLE I.—*Number of facilities and clients*

	Number of facilities		Number of clients	
	1958–59	1974	1958–59	1974
1. Residential facilities:				
Central institutions (regional centers)	6	11	5, 874	5, 556
Local institutions	14	28	2, 024	2, 374
Relief and holiday homes	1	7	18	47
Special treatment homes	0	2	0	9
Homes for children	0	2	0	26
Treatment home (delinquents)	0	1	0	5
Boarding schools	3	1	625	54
School homes	3	18	83	298
Youth boarding schools	0	5	0	107
Hostels	1	32	15	656
Semiprivate care homes	26	19	612	365
Total residential facilities	54	126	9, 251	9, 497
2. Day facilities:				
Schools	19	72	1, 150	3, 734
Kindergartens	5	51	177	880
Workshops	3	50	85	2, 674
Youth schools	0	3	0	152
Total day facilities	27	176	1, 412	7, 530
Total	81	302	10, 663	17, 027

Furthermore, the number of mentally retarded people receiving merely a passive type of services has been reduced to a minimum.

We find that the total number of clients of residential facilities barely increased throughout this period—from 9,251 in 1958-59 to 9,497 in 1974. There is an actual decrease from 2.0 to 1.8 per 1,000 population in 1974.

The number of such facilities, though, has increased from a total of 54 to 126. This also means that their size has decreased considerably. The average number of beds per institution in the first part of the period was 170, whereas in 1974, it had decreased to 75 beds per institution.

Furthermore, residential facilities are now dispersed through a much larger number of categories. At the beginning of the period, there were seven categories, at the end, eleven.

Finally, the nature of the facilities has changed considerably. At the larger as well as at the smaller facilities, the residential units are smaller and more comfortable. The role of the staff is no longer that of merely supervising residents—today, they function more as specially trained teams of skilled people. In other words, a more active and humane environment has been established. Another contributor in this concept is the two-enviornment principle—the separation of housing environments and working activities—which is being practiced as widely as possible.

Providing single rooms for the greatest possible part of the clients has been a development of the utmost importance. The institutional service of 1958-59, like services in many other countries, was characterized by dormitories with 30 or more residents in each primitively furnished room.

In Denmark there has been a constant endeavor toward breaking down these monstrous living conditions (sleeping silos) and the objective has been single rooms for all who could benefit from them—which has proven to be most of the mentally retarded beyond infancy. Table II shows how far we had progressed in 1971. The development toward providing single rooms has continued since.

TABLE II.—*Rooms and beds by size of rooms, February 1971*

Beds per room	Rooms	Beds	Percent of beds
1	1,474	1,474	15.0
2	932	1,864	18.9
3	455	1,365	13.9
4	364	1,456	14.8
5	123	615	6.3
6	116	696	7.1
7	41	287	2.9
8	86	688	7.0
9	39	351	3.6
10 to 14	53	580	5.9
15 to 19	14	230	2.3
20 to 24	7	152	1.5
25 to 39	3	79	.8
Total	3,707	9,837	100.0

The reduction of residential services is due to efforts to help families keep retarded children in their own home and the assistance to young retarded people to establish their own independent homes and lives. The breaking down of institutional care has gone along with the enormous increase throughout the period of day-care facilities. This is illustrated in the lower part of Table I from which it appears that the day-care service—consisting in 1958–59 for the country as a whole of 19 schools, 5 kindergartens and 3 workshops with a total day-care capacity of 1,412—in 1974 has developed into 72 schools with a capacity of 3,734; 51 kindergartens with a capacity of 880; 50 workshops with a capacity of 2,764; and 3 youth schools with a capacity of 152. This means that throughout this 15-year period the day-care activities have increased by more than fivefold. For some of those in residential care, day-care activities take place within the facilities but these are practically always in separate buildings. To a larger extent, however, these clients, too, will have day-care activities outside the residential facility.

Finally, the need of the retarded for service at either a residential or day facility has been considerably reduced through their opportunity of drawing—along with other citizens with a reduction in occupational abilities—a disability pension. This was achieved in 1965 on an individual evaluation (earlier the disability was only estimated). The disability pension meets a realistic living cost, so that many mildly retarded people have been enabled to establish an independent life of their own with no need of special protective arrangements.

The number of mentally retarded people living independently in rented premises or in a flat is increasing considerably. Apart from the Disability Pension, society is able to place apartments at their disposal and subsidies can be offered as they are to so-called normal people.

Undoubtedly, this is also one of the factors behind the development of a situation where the frequency of persons registered under the service for the mentally retarded has not increased during the last years but still stands at 4.4 per 1,000 inhabitants.

Future Projections

A genuine long-term plan for services for mentally retarded people has not, as yet, been made—what has been made, however, is a long-term projection on the assumption that present development and present policies are maintained. This projection is based on a prognosis of clients, based on the experiences of a great part of this century. The development of services has been applied to the prognosis as a percentage distribution of services needed for each single age group.

Biography

N. E. BANK-MIKKELSEN was born in Denmark in 1919. He received a law degree at the University of Copenhagen in 1944. During 1944 and 1945, he worked in the resistance movement. He entered the Danish Ministry of Social Affairs in 1946, and the Danish Service for the Mentally Retarded in 1950, becoming its director in 1959. Under his directorship, the Service has experienced a sixfold growth. Mr. Bank-Mikkelsen has lectured and consulted extensively around the world and in 1968 received the Kennedy Foundation award in recognition of his program development work. Since 1971, he has been director of the department for care and rehabilitation of the handicapped, National Board of Social Welfare.

16. Sweden
Karl Grunewald

Aims and Principles

Normalization

Normalization is the basic aim of all services for mentally retarded people in Sweden. This principle is applicable to the developmental program of the individual, whether child or adult, to the function of institutions, and to the actual organization of services. It is not affected by the fact that the majority of retarded people will never become fully adjusted to society; for differences in people's capacity to make this adjustment are purely quantitive and even the most severely handicapped person can grow. What the term implies is a striving in various ways to what is defined as normal.

Because it is based on equality, which is a concept deeply rooted in the mind of the majority of Swedes, normalization has been easily accepted by both professionals and the public; it has been debated very little.

For the principle to succeed, the following requirements must be fulfilled in any facility for retarded people:

- It must be organized on the principle of the small group—not more than 10 people living and eating together, preferably between 4 and 8.
- Communal facilities—like shared toilets, basins, showers and bedrooms—should be reduced to a minimum.
- The facility must be situated within a local community.
- It should not be larger than this local community can assimilate.
- The social contacts between facility and community should be freely developed.
- The people living there should be offered alternatives for weekends and holidays.
- The facility should consistently work in cooperation with relatives and with the retarded people themselves.

Integration

There has been increasing emphasis on integration in recent years. Integration, however, has to do primarily with the technical and organizational possibilities of coordinating services for mentally retarded people with other social services and ensuring that retarded people receive help within a general social framework rather than in isolation. Integration, in other words, is a means toward normalization rather than an end in itself. If it is overapplied, it can, for instance, isolate retarded people from friendship and social contacts.

The basic aim, then is to achieve the conditions of normalization. Retarded people should live in their own room, in a small group, and in a bisexual world. They should experience normal daily and yearly work in a different environment from the one they live in and be paid for their work and learn to handle money. They should be able to choose their own leisure activities. The environment should be adjusted to their age, and young people should have the chance to grow into adult activities and ways of life.

Development to Independence

Mentally handicapped people have very different degrees of dependence and so need a full range of housing, from the highly specialized to the completely normal. The aim is still, however, that all mentally handicapped people are totally integrated into their community.

We also believe that training for living is best done in an environment which is as close as possible to the environment in which the handicapped person will finally live rather than in special "training flats" in institutions which are used for only a few hours each day.

If we provide several types of housing, under the administration of a single organization, the mentally handicapped person will have the opportunity to move forward to increasingly normal and independent living conditions. This provides targets for him and considerable job satisfaction for staff. In practice, this means progression from hospitals to larger residential homes, then to smaller homes (hostels), to group homes, and to individual homes; from a centralized and specialized setting to a normalized setting integrated in the community.

This range of accommodation will, in the long run, give a more effective, more useful, and even a cheaper service. It is always cheaper when people live independently. Specialized housing is more expensive than ordinary housing and small facilities offer staff greater involvement and higher job satisfaction.

At this stage, it is vital to pay even more attention to housing and organization than to programs and personnel. Special housing lasts longer than either programs or personnel and, while they may be helped by a good physical setting, they can be badly hindered by an inappropriate one. Some purpose-built housing for handicapped people is so inappropriate to their needs that any training program will be bound to fail.

The Framework of Services

Legislation

A new Act on Provisions for Mentally Retarded Persons came into effect in July, 1968, superseding legislation dating from 1954. The act is a comprehensive one and, together with other legislation, covers all the special needs of mentally retarded people throughout their lives, as far as possible, within the normal framework of social services. The act is, therefore, a supplementary one to cover the special needs of a person who is retarded in his development. He still has all his ordinary rights as a citizen and entitlements under, for instance, the Social Welfare Act or the Medical Care Act. For many retarded people, special needs dominate and they are given full care. Others need help over only a short period of time or in specific areas of their lives; thus, for example, roughly twice as many people in each annual cohort are helped under the act during school age as during the years before and after.

The act is concerned with those who, by reason of retarded mental development, require special provisions from the public sector in their education, their adjustment to society, or in any other way. The term mental development relates to the intellectual functions, but the degree of retardation is not specified. The important thing to establish is individual need for the measures provided under the act. This does not mean that the act is more widely applied than it need be; particular caution is prescribed, for instance, when people are required to enter a residential establishment against their will.

Generally speaking, the classification of mental retardation in Swden has been narrower than in either Denmark or the United States. An upper IQ limit has traditionally been set at about 70 but this limit is very flexible and measurement of IQ has become less important as more tests have become available. Testing is, in any case, only part of overall assessment. The tendency is to become more careful about labelling a person mentally retarded.

Administration

Central administration of provision for mentally retarded people is divided between the Ministry of Social Affairs, the National Board of Health and Welfare, and the National Board of Education; their decision can be appealed against the government. Political and administrative staff serve primarily in the Ministry, while professional staff serve with the boards. The central authorities have the responsibility of insuring that the law is followed, programs are implemented, and standards are maintained.

Local responsibility for providing services under the act lies with the 25 County Councils. These Councils, whose members are elected every three years, are responsible for all local health services, children's homes, some vocational training, rehabilitation, and more. In each county there is a Board for Provisions and Services to the Mentally Retarded with administrative and executive power.

Broadly speaking, the central board deals with control, planning, and standards. They cannot dictate the detailed duties of the County Councils, as these are taxing authorities with their own constitutional powers. The boards do, however, have considerable influence through approval of all facilities, inspections, subsidizing facilities, published reports, and policy statements.

Finance

Care is provided free of cost to both the retarded person himself and his parents, although reasonable charges for board and lodging can be made if a handicapped adult has an earned income instead of a full disability allowance. Free care covers teaching material, text books, school meals, necessary daily travel to and from school, day nurseries and activity centers, dental care, speech therapy, physiotherapy, and such other medical services as can be provided at the facility concerned.

TABLE 1.—*Growth of combined expenditures (including investments) by the State, public health insurance funds, the counties and county boroughs*

Types of expenditures	Total expenditures		
	1959	1965	1972
Health and medical care, total	$436,000,000	$915,000,000	$2,889,000,000
Per capita	$58	$120	$356
Specific for mentally retarded of total expenditures (percent)	3.2	4.3	5

Parents of children under 16 living at home are entitled to a state nursing allowance (at present $2,600 a year which will increase about 75 percent in the next 3 years) if they need considerable special supervision over a long period because of physical or mental handicap; children under 3 are entitled to this only if their disorder is severe. Children in residential care qualify for the same allowance if they stay in their own home for a period of a least 10 days, with no limit in frequency.

Practically all retarded people over 16 who receive services draw a state invalidity pension which is the same as the nursing allowance. There are supplementary allowances for, among others, those with orthopedic handicaps and, in addition, most counties will pay special allowances if this will prevent an individual from going into an institution.

Most municipalites and communities have subsidized transport services for handicapped people, although these are available usually only for transport to and from work, education, rehabilitation and medical care.

The state reimburses the total cost of technical aids for handicapped people, including not only the obvious items but often aids to daily living which have not been specifically designed for the disabled, such as typewriters, tape recorders, and dish washing machines. There is also state aid for specially designed equipment in residential units for severely handicapped people. Most of these and other regulations involve the municipalities or County Councils and many have adopted additional regulations to supplement the basic services.

Sweden has no quota system to require employers to take on handicapped workers. The state, however, pays 40 percent of the wages of any handicapped employee. Although this offer applies equally to employees who later become handicapped, it has not yet had any great effect.

TABLE 2.—*Total number of mentally handicapped receiving provisions and services*

	Number of persons		Percentage of the population of Sweden (8 million)	
	1969	1973	1969	1973
Children and youths (CA 21)	8,460	13,760		
Adults	18,350	18,370		
Total	26,810	32,130	0.34	0.40
In 24-hr care	15,600	16,000	.20	.20

The Range of Provision

Under School Age

There are still children who would profit by some form of day care and preschool experience, as well as by care in the home, who are not receiving these. However, relatively few of them need residential care and there are practically no waiting lists for this age group.

Mentally retarded children under seven—and with no lower age limit—have the right to preschool instruction. If no class is available in their district, they have the right to five hours of teaching at home per week. In all, some 1,300 children are in preschools; 67 percent of them live with their parents, 20 percent in residential homes, and 12 percent in boarding homes.

TABLE 3.—*Number of classes for mentally retarded children and their location, 1969 and 1973*

School classes	Preschool		Basic school		Training school		Vocational school		Total	
	1969	1973	1969	1973	1969	1973	1969	1973	1969	1973
Integrated with ordinary schools	1	50	200	357	33	113	10	60	244	580
In separated special schools	58	82	53	61	66	104	36	70	213	317
At boarding schools	36	38	177	123	71	89	56	94	340	344
At residential homes	27	51	...	...	86	107	2	23	115	181
Total	122	221	430	541	256	413	104	247	912	1,422
Number of pupils in each class	4–7		6–11		4–8		6–11			

The trend is increasingly towards bringing retarded children into ordinary preschools. To bring one or two handicapped children into the class, its overall size may have to be reduced slightly. A special assistant is usually employed and the preschool teacher, who will usually have had very little training in dealing with handicapped children, should also receive special guidance.

School Age

All children of school age who need services now receive them. Education is compulsory for all mentally retarded children from the age of 7 to an upper limit of 21; 9,400 children and young people have special class teaching and a further 1,700 receive individual tuition, which in practice means a maximum of five lessons a week.

At the approximate age of 20, many mentally retarded people have, for the first time, a real motivation to learn "school subjects." We have, therefore, developed "study groups" for them which cover a primary level of reading, writing, and arithmetic, as well as English and all kinds of cultural activities in once or twice weekly sessions. In 1970, the largest study organization in Sweden ran 2,700 of these study groups for retarded people.

Sweden's "folk high schools" were originally designed to offer adults a chance to continue their education; in recent years they have begun to offer special courses to mentally handicapped people. We find that the most important element in these is the contact between the ordinary students and the retarded ones.

Adults

Some 5,000 mentally retarded adults, mostly mildy or moderately retarded and living in relative isolation from towns, do not have the occupation they need in a training center or sheltered workshop. They receive a pension and live either independently or with relatives, but some would profit by living in a group home and a few by the life of a residential home.

Day activity centers for adults have increased considerably over the last few years in the community as well as in all residential homes and special hospitals. Two-thirds of those who attend community day centers live with their families and 15 percent in group homes; they make up 12 percent of all adults receiving services. No adult is too handicapped to be admitted to a day activity center; those few who cannot take part in organized activities for any length of time receive daily care nevertheless.

TABLE 4.—*Day facilities for adults, 1974*

Day facilities	Number of facilities	Number of persons	Average number of persons/facility
Day activity centers (training centers)	134	2,920	22
Sheltered workshops	31	870	28

Sheltered workshops are geared entirely to production. In addition to those in special workshops, some 600 retarded people have been individually integrated into ordinary sheltered workshops. In all, 10 percent of adults receiving services are in sheltered workshops, 43 percent living with their families, 17 percent in residential homes, 18 percent in group homes, and 20 percent in their own home. Sheltered workshops used to be built in conjunction with residential homes, but we discovered this to be a mistake early on. We now attached sheltered workshops for retarded people to similar facilities for other handicapped groups, and the majority of our workshops are now part of a larger unit; this brings better opportunities for gradual integration of mentally handicapped people with other handicapped groups.

The Board of Provisions and Services to the Mentally Retarded is required to help retarded people get a job of their own if they can handle one. Many then need no further help from the board; while 1,500 are still under its supervision, 43 percent of these live with relatives, 31 percent have their own homes, 11 percent live with another family and the rest live in a residence.

Patterns of Living

Care at Home

Particularly in their formative years, it is essential that mentally retarded children have the opportunity to be with other members of their family and to establish contacts with the community at large. The present trend is to offer increasing help to parents through counselling and various types of day activity and this can prevent unfortunate final placement in an institution.

For adults the objective is different. Following the principle of normalization, the aim should be to enable them to move to a boarding home or to their own flat, perhaps with certain supervision from relatives or staff of the board.

The Provisions Act states that if a mentally retarded person needs care, but should not be in institution, then the Board should provide this care in his own home. Here mentally retarded people are pioneers; they are the first group for whom such a radical enactment has been introduced.

Care at home includes regular visits by medical staff, homemakers, occupational and speech therapists, physiotherapists, social workers, and so on. Children can also, if they are not in a preschool group, receive teaching at home. Every effort is made to coordinate these activities together with those run by bodies outside the authority of the board.

The effect of increased support to parents has been very noticeable. They are now much more willing to keep their child at home—sometimes with interruptions for short-term institutionalization. As we have noted, only a few County Councils now have waiting lists for admission to an institution for children.

Foster Homes

Recently we have had some success with a fostering program for small children. A child who seems a burden in his biological family may be an asset in a foster home. Placing a severely handicapped child with a foster family must, however, depend on access to adequate preschool and school facilities in the neighborhood. Nowadays a child with uncomplicated Down's Syndrome, for instance, is seldom placed in long-term residential care. Generally speaking, mentally retarded children should either stay in their own home or go to foster parents. Any type of institutional placement—other than for short-term observation—should be avoided.

Residential Care Principles

Social Adaptation

Good social adaptation presupposes transfer training and transfer demands a small and stimulating environment. Individualized and well-structured influence techniques are needed if the handicapped individual is to to achieve the greatest benefit from the stimuli of a small environment.

This environment must be socially real. It is impossible to build up substitute situations within institutions for the retarded person who needs training in a situation which is identical to that in which he is eventually going to function. This means that we must offer social environments and situations in which retarded people can apply freely and naturally what they have learned in a specific instructional situtation. This is important when we come to consider where in a community a residential home should be situated.

This is why in Sweden we build large numbers of fairly small units in the middle of their communities, more or less specialized for the functional level and current needs of the retarded people who live in them. Children and adults are separated as far as possible.

This means that the individual, as he progresses, will have to move more often. Many people see this as a disadvantage; they feel it good for the retarded person to remain in the same place for his entire life. We, ourselves, however, often experience economic or personal development or renewal when we change our place of work or residence. Why should this experience be restricted to nonhandicapped people?

We try, when designing services for retarded people, to separate residence, occupation, and leisure time and we apply the same formula, as far as possible, to institutions which offer 24-hour care. We try, for instance, to put a geographical distance between the school and the residential home and between all other living places and the daily occupation. This also means that we try, as far as possible, to offer retarded people existing local leisure and recreational facilities, preferably on an individual basis.

The Small Group

People working in institutions have long since observed that severely retarded people appreciate a "small environment" in which the number of interactions with other people are few and that moving from a large ward to a group of 10 or less has a positive effect. The retarded person's reaction suddenly becomes predictable and he can recognize and grasp reality. Development is encouraged partly through offering the retarded person a small number of relationships—potentially stimulating rather than frustrating—and partly through the homelike atmosphere and equipment of the unit. Homeliness may have to be modified to cope with more-or-less permanent medical conditions or additional handicaps, but the starting point in all planning should be a normal, homelike and small environment.

The Heterogenous Group

In a guided environment, relationships between residents are perhaps even more important than those between them and staff. The composition of a small group of people must be carefully planned within the limits of the overall grouping (children or adults) to be as heterogenous as possible. This means *not* segregating people with physical handicaps—the blind, for instance—into special units. The distribution of these "minorities" through all units reduces the number of multiply-handicapped people in any one unit and offers them a richer and more active environment than they would otherwise have. For this to be possible, however, there must be enough specialists and specialized services available and the unit must be properly equipped to deal with additional handicaps.

This fundamental principle may have to be waived for deaf adults and school-age children. In general, however, the most retarded people should always be in a minority within the group so that they may be "drawn upwards" by the others. The span of retardation within the group should not, however, be so great that some of its members cannot gain from group activities.

Individual Rooms

We have underestimated in the past the need of mentally retarded adults for their own rooms. Yet we know, from our own experiences, how we identify ourselves with our own rooms, the furniture and walls, and how the whole room becomes part of us. Mentally retarded people today have very limited opportunities to understand themselves, but one way they can do this is through the material around them. Their room becomes part of them and they are able to build up a sense of identity; their ego and individuality mature through the room and through the things they collect and like to have around them.

If we compare a mentally retarded youngster with a room of his own to a boy of the same age and functional level in a boarding school or hospital, we soon see the difference. It is practically impossible to build up all that an individual requires in the crowded atmosphere of an institution. We have learned, too, that aggressive young people tend to calm down and begin to feel more secure if they learn to live in a room of their own with their own possessions.

Overall, 48 percent of places in Swedish residential facilities are in single rooms. Another 34 percent are in double rooms.

Sex and Residential Care

Previously, we tried to keep not only units but entire homes for men separate from those for women. In the last decade or so, policy has completely changed. All our homes are now approved for both sexes and three-quarters of them, in fact, cater to both men and women as do many units within these homes. The idea behind these mixed units is that tolerance and general satisfaction with life should increase and that the retarded people will become calmer and more interested in their appearance and behavior. Now 73 percent of group homes—housing an average of 7 people each—are for both men and women and 93 percent of staff agree with this policy.

Detailed interviews with retarded men and women living in residential homes have shown that many of them because of their ignorance and isolation, experience great apprehension and sometimes anguish when they are faced with sexual situations. Special teaching materials on this matter now exist.

Residential Care for Children

Boarding Schools

There are 26 traditional boarding schools with an average of 75 places (see Table Three). There is now, however, a very strong tendency not to build more of these and to replace existing ones with group homes.

Boarding schools and homes are mainly for children living far away; ninety-five percent go home for weekends. The group homes have an average of six children in a small flat or house. Our plan here, and it is a sincere one, is for an exodus from the boarding schools. This started with special classes within normal schools for "educable" but also some "trainable" children; because these classes are decentralized, the children can either stay in their own homes or live in a group home.

Residential Homes

The majority of these homes are approved for children up to seventeen years of age and this is where our most severely handicapped children live. All but five of the twenty-five County Councils have recently built or are building new homes. (See Tables Three and Five for details of size, etc.)

TABLE 5.—*Type of residential facilities, 1974*

Type of residential facility	Number of facilities	Number of persons	Average number of persons/facility
Group homes for adults	202	1,430	7
Boarding homes for children and youths: [1] [2]			
Integrated in community	90	530	6
At boarding schools	26	1,940	75
Residential homes for adults	122	9,270	76
Residential homes for children	[3] 48	2,280	48
Residential homes for blind and deaf adults	3	240	80
Special hospitals [4]	6	1,430	238

[1] Group homes for youths are included here.
[2] Refers to 1973.
[3] 12 of these residential homes are on the same ground as residential homes for adults.
[4] For retarded persons in need of special care.

TABLE 6.—*Forms of living of all the mentally handicapped receiving provisions and services*

Form of living	Number of persons		Percentage	
	1969	1973	1969	1973
Parental homes	9,580	13,490	35.7	42.0
On their own	340	1,350	1.3	4.2
Other private homes (foster homes)	900	1,060	3.3	3.3
Boarding schools and group homes (children)	2,640	2,240	9.8	7.0
Group homes (adults)	350	1,170	1.3	3.6
Residential homes	10,100	10,790	37.7	33.6
Special boarding schools	180	120	.7	.4
Special residential homes	280	220	1.0	.7
Special hospitals	2,030	1,450	7.6	4.5
Other forms of living	420	240	1.6	.7
Total	26,820	32,130	100.0	100.0

A couple of homes take children only for short-term care; one of them specializing, during the summer months, in children with severe orthopedic problems. The other homes increasingly accept children for short stays to give their parents a rest or for observation and setting up new treatment; there are now about 200 places for short-term care.

Practically all the homes for children planned in recent years are in or near a town with a general hospital. This means access to the pediatric and child psychiatric departments, and specialists have increasingly been engaged as consultants to the homes.

Passive care has been transformed into active care. There are now methods for social training for even the youngest and most severely handicapped child. For consistent implementation, however, we need far more participation from child psychologists and trained staff—including physiotherapists, speech therapists, and specially trained teachers—than there is at the moment.

The emotional isolation of residential homes for children is now being overcome. For decades, nursing staff, without specialist support, have had no other aim than to provide the best possible nursing, usually without any contact with relatives. Aims and training programs can now be defined for every child and as a rule the parents maintain contact and sometimes take them home for weekends and holidays.

Residential Care for Adults

Group Homes

Most group homes have been set up in recent years. (See Table 5) We intend to open about 30 a year over the coming years. Group homes seem to us to be the best approach to integrating mentally handicapped people into their community. They give ordinary people opportunities to meet handicapped people and to get to know them as individuals. This is the way attitudes change; not only this, but surveys have shown the greatest changes among people who have had the most contact with retarded people. Even though intellectual attitudes in general appear to remain unchanged, people's emotional attitudes toward retarded people they know have changed for the better.

A group home is generally made up of two flats, each for four people, or three or four units with flats for one or two people, close to a "mother flat" for four or five. Two-thirds of the accommodations in group homes consist of single rooms and nearly all the others are rooms with two beds. The majority of those living in group homes are mildly retarded; some "borderline" people stay for some time and then move to more independent living. However, the trend is now to take moderately mentally handicapped people into these homes as well. Forty percent of men and women in group homes attend training centers, about 30 percent have sheltered employment, and the rest of them work in open employment or have other occupations.

Up to half of those moving to a group home come from a residential home, though some people come directly from their parental home. To our surprise, half the residents who had lived for some time in a group home were in one year able to move to a flat on their own. Sometimes a woman and a man were able to move together into a flat, often still a unit of the group home. In all, 1,400 people live on their own, most of them passing through a group home. Here are the "savings"—economically and psychologically.

A group home is usually started by acquiring one home to which several annexes in the neighborhood are then added. In this way the staff are able to supervise easily, while the mentally handicapped people have easy access to the "mother home" for leisure time and special festivities.

In group homes for adults the staff do not live in the same house or flat and only exceptionally does a member of staff stay overnight. On the whole the residents need little help and supervision as far as work is concerned, although they require continuous advice in the planning of leisure activities and personal relationships.

There was some opposition from the community when the first group homes were set up. Mistakes were made. "Detached" houses were bought and the mentally handicapped people became really "detached" and isolated. Rows of terraced houses were not much more successful. But when the number of residents in each home was reduced, so was the opposition. It has also proved inadvisable to prepare the immediate neighbors well in advance. Surveys have shown that neighborhoods were often not even aware of the existence of group homes which had already fitted unobtrusively into community life and that many people accepted them spontaneously.

Residential Homes

These are socially oriented, community-based institutions which provide living accommodation and social rehabilitation for 34 percent of the mentally retarded population (see Table 6). They are not medical institutions; the director or warden is usually a trained social worker and the staff are not medically trained.

TABLE 7.—*Total number of hospitals, residential homes and boarding schools for children and adults (except group homes) according to number of beds*

Type of facility	Number of beds						Total number of facilities
	50 and less	51–100	101–200	201–300	301–400	401–500	
Boarding schools	8	13	5				26
Residential home for adults[1]	63	29	17	7	4	2	122
Residential homes for children	24	11		1			36
Special hospitals	1		3			2	6
Total	96	53	25	8	4	4	190

[1] At 12 of these residential homes, beds for children are included.

Sweden has altogether some 122 residential homes which care for 9,300 retarded adults. Their size varies between about 10 and 430 places and the average number of places in a home is 76. The general aim is to avoid homes for more than 200 people; 100 places, at most, is preferable in many ways, particularly as only then is it possible to situate the home in the community.

The average size of departments (wards or units) within the institution is 11.5 persons, and bedrooms are now built only for one or two. Less than one percent of all those in residential homes for adults live in rooms with five or six beds, the others all in smaller rooms.

In principle, residential homes should fulfill the functions of an ordinary home. This is why living rooms and dining rooms are attached to each department or unit, which must also have enough staff and equipment for retarded persons to be trained to a maximum degree of independence, both socially and in the various activities of daily living. The design of the premises and, of course, the qualifications and training of the staff are both of particular importance.

There still exists a group of retarded people who are classified as "difficult to handle" and who usually have in common certain traits of aggressiveness, hyperactivity and impulsiveness. Experience shows that the most important factor in their rehabilitation is living in small groups with increased opportunities for active care and adequate training for employment in some form of sheltered activity. In most homes for adults, all the residents take part in regular day activities, mainly of an industrial or occupational-therapeutic character. In homes with many severely retarded people, the figure falls to about 70 percent.

Retarded people with severe orthopedic handicaps require special facilities. With recent improvements and better technical facilities, a considerable number of these people can be cared for in residential homes. Even more important, the number of invalids has been so reduced that there are practically none at all in the smaller homes and only a few in the larger.

Each County Council usually has a number of residential homes. To achieve a suitable range of equipment, structure, and staff, one of these is usually designated in each county as a central residential home. The others then function largely as annexes to this home and are called local homes. Central residential homes have, on average, 200 places; the others only 42. A third of the local residential homes are privately owned institutions although the County Council pays the entire daily charge for care and also decides who should be admitted.

Special Hospitals

The special hospitals care for 1,450 mentally handicapped people or 4.5 percent of the mentally handicapped population (see Table 6). There are 6 hospitals with 240 beds on average (see Table 5). Until 1967 they were administered by the state but were then given over to the counties to be coordinated with the other facilities for mentally handicapped people and to be directed under the same law.

These hospitals specialize in the treatment of delinquent or antisocial men and women, as well as in the care of the profoundly mentally handicapped person who cannot be managed in other facilities. Some people are sent from the courts to the hospital for care and assessment, and most of them progress from there to residential homes. Hospitals provide more and more short-term care to assist the residential homes instead of traditional long-term care. Staff are medically trained and there is a strong emphasis on medical aspects of care.

Since 1969 no children have been cared for in special hospitals although one of them does still specialize in orthopedically-disabled, mentally retarded children. Overall, nearly 8 percent of the adult retarded population are at present in 24 hour care in one hospital or another. This figure will continue to decrease, probably by half over the next 10 years.

The number of retarded people characterized as being antisocial will depend largely on how actively society helps the retarded person early on so that his uncontrolled behavior does not reach the stage of criminal activity. In all countries the custodial care of this group constitutes a special problem, largely because it includes a small number who require different forms of care and confinement from the majority of retarded people. They include those committing criminal and delinquent acts, sexual offenses, arson, and so on.

Two characteristics of the mentally retarded person with antisocial behavior may be mentioned here:

- Preventive measures in the form of close supervision, the provision of accommodation and employment, and organized recreational activities achieve greater results with mentally retarded people than with any other group in danger from antisocial behavior.
- Mentally retarded individuals may on occasion commit serious criminal acts, perhaps violent in nature, but the treatment which should follow may be quite mild in comparison to what is necessary for a normally intelligent person committing the same offense. This discrepancy between symptom and treatment is peculiar to mentally retarded people.

It is vital that any differentiation within the heterogeneous group of antisocial retarded people should be made with due consideration of the special type of care that is desirable or necessary. At the same time, it is important that the units thus created should not cover population areas larger than a region, since the geographical distance from the retarded person's home community is always an important and sometimes a decisive factor in the social rehabilitation program. As with all other "psychopaths," some mentally retarded people in this group require, at least for some time, relatively strict custody in a locked unit, with special observation and special procedures and attitudes from the personnel responsible for the rehabilitation program. These wards are incorporated in the special hospitals.

Only 10 years ago, 900 adults were still under care at our special hospitals because of antisocial behavior. Over 500 of these have since been discharged to less restricted accommodations and a further 100 have been discharged as not mentally retarded nor even in need of care. We reckon that for Sweden, as a whole, we need less than 200 places of this kind; i.e., about 2 places per 100,000 population. This category of retarded people has thus decreased considerably.

There are apparently no retarded persons in any Swedish prison, nor in any of the special departments at mental hospitals.

The Cost of Residential Care

There are at least two reasons for the lower cost of homes with a smaller number of beds; there are relatively fewer people with additional handicaps in the smaller homes and these homes are cheaper to run and administer than the larger ones.

The point is, however, to have a whole sequence of residential facilities in a region, so that no one receives more total care than he needs. The number of people discharged to independent life is a proof of the dynamics of the systems. (See Table 8.)

TABLE 8.—*Daily cost for mentally retarded adults, 1971*

Type of facility	Dollar value	Number of beds in average	Total number beds, 1974	Percentage
Hospitals	34	333	1,430	10.6
Central residential homes	19	175	4,000	29.6
Local residential homes	14	45	5,270	39.0
Group homes	[1] 8	8	1,430	10.6
Own living	NA[2]	NA	1,400	10.3
Total			13,530	100.0

[1] To the cost of group homes has to be added a cost of up to $8 per day for those 40 pct who work in a day center.

[2] Practically all of them contribute to their living—many pay the whole cost.

Some Legal Questions

Marriage

There is no longer any general ban on marriage for retarded people in Sweden. If the person concerned understands the legal implications of marriage, he is also entitled to marry. Those with a guardian, however, must obtain his permission; if this permission is not given, the case can be considered by a court. The entire question of marriage has been seen in a different light since, in recent years, it has been generally recognized in Sweden that adults can live together without being married.

Various studies made in Sweden have brought to light the following: that retarded women marry more often than retarded men; that retarded people seldom marry each other; that the percentage of retarded women who bear children is half that for nonretarded women; that when retarded women do have children, (they have more children than nonretarded women; that retarded women find a major difference between handling one child and being able to cope with several; that retarded women have retarded children (all types included) only slightly more frequently than nonretarded ones do.

Sterilization

The 1941 Act on Sterilization stipulates that persons who can be expected to pass on hereditary mental illness or deficiency to their children can be sterilized as can persons who, by reason of mental retardation, are considered clearly unsuitable to have custody of children in the future. This act presupposes the consent of the person concerned but those who are incapable of giving their valid consent because of mental disorders can be compulsively sterilized without their consent. This latter solution is used very restrictively.

Since the early fifties, only very few retarded persons have been sterlizied—in the last 10 years only about 30 each year. There are several reasons for this restrictive policy. It is very difficult to judge in advance who, among those for whom the question of sterilization arises, may later in life become capable of managing parenthood and who will not. Sterilization is a definitive operation which cannot be reversed if the person concerned should subsequently mature, and it is often psychologically traumatic. There exist at present other ways of preventing undesirable pregnancies; for instance, counselling on birth control and contraceptives. The Act on Sterlization is currently under review.

Special Status in Criminal Law

The Swedish Penal Code states that a person reaches the age of criminal responsibility at 15, after which he can be tried for offenses before a court of law. Mentally retarded persons are no exception. Following the policy of normalization, mildly retarded people are increasingly being treated like other citizens as indeed is their human right.

A person who has committed an offense as the result of mental retardation, however, must not be sentenced to prison. The court can decide to commit a mentally retarded person for care at a special hospital if it finds—after special psychiatric examination—that he needs such care.

Conclusion

Some Prerequisites

If a dispersed and decentralized service system for mental retardation is to work smoothly, it must be kept together by one organization dealing with administration, economics, personnel and programs. In Sweden this is done by a special board in each county.

Admittance to and discharge from the different facilities must be decided by the same group of people. Otherwise it is only too easy for a mentally handicapped person to be kept, because he is useful there, at a type of facility which will not encourage his progress. On the other hand, even though "habilitation" means upward and forward, the system must provide for those who have to return to more sheltered conditions after having been given every opportunity and encouragement to live more independently.

In Sweden it is the same experts—a team of a director of social welfare, of school and of residencies—who keep the system together and follow the handicapped person for as long as possible. They work independently of any institution, except the special hospitals from a formal point of view.

The special organization for mentally handicapped people must develop a service system based on family care of children and independent living of adults as different types of day facilities. Sheltered workshops and training centers for adults are, for example, a prerequisite for living in group homes. So is a subsidized transport system. Residential living must be a part of the same service system.

As a result of the normalization of the environment of mentally handicapped people, leisure activities have become as important as living and working activities. Throughout Sweden there are now specially trained staff organizing such activities. This training is regarded as part of the adult education of mentally handicapped people which also includes, still in too small a degree, education about sex and alcohol.

One prerequisite for a developing and differentiated system or service for retarded children and adults is a strong and well-informed parents' organization. The associations in Sweden do not run any facilities with the exception of summer homes and a small home for short-term care. Their most important function is that of a pressure group.

The Future

Three factors have been decisive in the development of provisions for Sweden's mentally retarded people:

- A deeply rooted respect in the Swedish population for the value and potential of each individual even if he or she cannot participate in production.
- A real conviction that mentally retarded people can be helped.
- The fact that the public sector bears the total social responsibility for those citizens in need of help.

The total number of retarded people is considerably lower than in the majority of non-Scandinavian countries even if the same definition is applied (see Table 2). This is probably because, above all, cultural deprivation, malnutrition, and comparable environmental factors are practically nonexistent in Sweden. The rate of immigration is comparatively low and mainly from the other Nordic countries.

The number of stillborn children has continued to fall in recent decades as has the infant mortality rate. This means a relatively large increase of children over a 10-year period who survive pregnancy, delivery, and the first year of infancy. Many believe this to have been achieved at the expense of an increased number of children with permanent brain injuries even if the number is relatively small. This, however, is wrong. We are acquiring steadily improving methods of preventing brain injury during pregnancy, delivery, and infancy. The early medical psychological, and pedagogical habilitation of injured children, also brings good results. It should not be forgotten that these techniques benefit all injured children.

There is thus clear evidence that the number of injured children has already been reduced. The number of children with cerebral paresis, for instance, has fallen significantly in the 1960s, those with mental retardation included.

As to the hereditary forms of mental retardation, we know that those resulting from specific injured genes are more frequent in marriages between relatives than otherwise, and consequently occur more frequently in geographically isolated areas. Sture Rayner[1] has shown that such diseases have fallen by 50 percent in the space of 30 years, thanks to the decrease in isolation among the Swedish population.

Polygenic mental retardation has also declined as geographical isolation is overcome. Rayner, in the same article, shows how the number of mild cases have fallen to one-quarter of what it was in a given municipality in the late 1940s. Considerable gains are surely still to be made in this area.

The incidence of mental retardation is thus falling but the prevalence is rising owing to the greater life expectation. In the 1950s we calculated an excess mortality among mentally retarded people of between 30 and 40 percent. Forssman and Akesson[2] studied length of life in practically all retarded people in Sweden in the 1950s and 1960s. The total group had a mortality rate of only five percent above normal and length of life was practically normal for those with mild and uncomplicated mental retardation.

The most important reasons for the increased length of life are probably the introduction of antibiotics, improved standards of hygiene at the living facilities, smaller units and bedrooms, a higher standard of diet, etc.

Obviously this development will influence the number of adult retarded people very strongly in coming years. Our programs are already influenced; we are providing more day training centers and group homes. On the other hand, we already need fewer beds in residencies for children.

We are now in a position to move from the stage of differentiation to that of decentralization and integration. How far is it possible to combine more specialized care (which can lead to relative isolation) and coordination with services to other handicapped and nonhandicapped groups (which can complicate meeting the retarded person's specific problems)? This is a delicate balance which demands sensitivity to various trends in development. The retarded individual should be regarded as only one among all others who need some form of support or service. This will in the future mean fewer people being admitted to the special service for the mentally retarded.

A normal person is just like normality in general—an ideal fiction. But an abnormal person is no fiction at all. Therefore, our goal will always be to help the handicapped person to an optimum level of independence.

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Biography

KARL GRUNEWALD was born in 1921. He received his M.D. degree at the University of Lund, Sweden in 1948, and in postgraduate studies, he specialized in child psychiatry and pediatrics. In 1950, he participated in the Swedish Red Cross Mission to Korea, and from 1956 to 1960, he was head of the department for child psychiatry at Kristianstad Hospital

Since 1961, he has been head of the division for care of the mentally retarded of the Swedish National Board of Health and Welfare. He is a member of the World Health Organization Advisory Panel on Mental Retardation; since 1967, he has been chief editor of the journal *Psykisk Utvecklingshamning* (Mental Retardation) and the author of several books in the field of mental retardation.

17. Ontario

Donald Zarfas

Background

Ontario has a population of approximately 8 million, mainly along the southern border of its 360,000 square miles. It has eight principal cities, the largest of which is Toronto with a population of over 2 million. There are 36 smaller cities spread throughout the Province, and a vast, sparsely settled territory in the north. Ontario's climate is temperate in the south because of its proximity to the Great Lakes; but in the north, winters are long and cold. The population of the Province is principally English-speaking but there is a significant number of Italian-speaking people, many of whom are recent immigrants in the Toronto area. There is a somewhat less concentrated but even larger French-speaking population, mainly along the Quebec border and in Northern Ontario.

Programs especially for retarded people began as long ago as the mid-1870s. These programs have neither been so far ahead of the pack as to be outstanding, nor so far behind as to be out of date. There have been pockets of excellence with some pioneering, and there remain pockets of disgrace which are beginning to benefit from changing patterns.

Around 1870, there was recognition that retarded people were ill-provided for in the jails and mental hospitals in the Province. Finally, in September 1875, the first institution, the Asylum for Idiots in Orillia, was established in a refurbished hotel. Although perhaps unsuited for this use, it provided an opportunity to bring retarded people together for training. This concept was based on the then current ideas propounded by Guggenbuhl and accepted throughout Europe and the United States.

The programs, in those days, were based in Itard's physiological form of treatment, as developed by Seguin. Dr. Alexander H. Beaton, superintendent of the institution and ninth President of the American Association on Mental Deficiency, not only encouraged the legislature to provide funds for a very advanced educational program, but succeeded in having them replace the old institution with a new physical plant.

Unfortunately, shortly after the new facilities opened, the development of the eugenic movement, along with the frugal ideas of our legislative forefathers, saw the budgets cut and the fine teaching programs degenerate to custodial care.

In 1912, with a significant resurgence of interest, the first community-based educational programs for mildly retarded persons were started in the City of Toronto schools. In 1915, the first Parents Association was formed and in 1916, the first diagnostic and assessment center was established at the Toronto General Hospital by Dr. C. K. Clarke, an internationally famous psychiatrist. However, post-war montetary problems and fear of the retarded meant that the Parents Association and the diagnostic services passed into history.

The first notable re-establishment of programs directed toward the training of retarded people began about 1928 in what is now called the Ontario Hospital School, Orillia. New modern workshops were established and individual training programs were instituted by a forward looking Superintendent, Dr. B. H. McGhie, who had the support of the Department of Psychology of the University of Toronto. The programs developed by this progressive group are still worthy of consideration today.

Unfortunately, again the climate changed and the devastating depression of the 1930s brought most of these programs to a halt. Because the workshops' manufactured articles were in competition with industry, the protestations of both labor and industry resulted in the closing of the workshops and work-training programs. Similarly, the almost daily demands of the Provincial Office to limit spending—not an entirely foreign notion even in affluent times—again reduced the programs to mainly custody. In 1939, although money was more readily available, staff were not because manpower was called to a much more pressing emergency.

In the immediate post-war years and into the mid-1960s, there was little money and little interest in developing and improving services for retarded people. The mental retardation programs were carried on the coattails of the mental health movement and they received the smaller portion of a not-too-plentiful budget. The two most descriptive terms for institutions for the retarded during those years were overcrowded and understaffed.

For many years the politician held the key to admission to a facility. In their desire to help obviously distressed constituents, they requested the administration to admit retarded people without preassessment of the child's or the family's true needs. Admission was seen as a panacea and the retarded person was out of sight and, unfortunately, out of the mind of the same politician at the time of the annual presentation of the department's fiscal estimates.

Poor financial support was, perhaps, inevitable as Ontario was passing through a post-war period of tremendous growth. Demands for excellence in education at all levels, with the resulting huge demands on the public purse for universities, and more recently, for the development of community colleges, seemed to make retarded people the antithesis of this development and progress. During those years, new ideas, leadership and money for them were simply not provided to the Provincial Service.

Considerable movement, however, was taking place in the community. In the late 1940s, a small number of local Parent Associations started; initially, to improve the situation within the institutions. The need to develop community programs as an alternative to institutional living was, however, soon recognized. Local Parent Associations started to fund and operate schools for "trainable" retarded children.

In the late 1950s and early 1960s, the Provincial Government, recognizing the value of such schools, gradually increased financial support to the local associations, and next passed legislation to allow school boards to undertake such programs. However, it was not until 1965 that Ontario saw the need for mandatory legislation. Since that time, trainable retarded children have had the same educational benefits as those enjoyed by other students, including the mildly retarded, with the exception that financial support for trainable retarded children is one and a half times that offered to the secondary school student. Opportunity classes for mildly retarded children, which began in 1912, have now become available in virtually every community across the Province.

The local associations for the mentally retarded also initiated the development of community residences, sheltered workshops, preschool programs, leisure time and camping activities in many communities, all primarily for trainable retarded people.

In 1960, the Mental Health Division established the Children's Psychiatric Research Institute in London Ontario, with the author as its founding superintendent. CPRI was the first diagnostic, assessment, family counselling, and research institute in Ontario. The idea of providing services to families on a nonresidential basis was well received and the institute grew quickly in numbers and competence. A short term, in-residence treatment and training program was soon added to the outpatient service and the value of short term admission for treatment, training and family relief soon became apparent. Often diagnostic and assessment centers, on the same model but much smaller, were developed as either separate entities or as an outreach from the institutional facility. Now no retarded person in Ontario is admitted to a facility without an adequate preadmission assessment. Families and agencies are also able to have assessments of their children prior to admission to any service or when a crisis situation occurs and they require help.

Toward Change

It became quite evident in the early 1960s that the institutional approach to retardation was simply not attracting young, progressive-thinking professionals. Perhaps the overcrowding, the political influence on admissions, and the lack of communication between the institution and its catchment area had caused the dearth of medical staff. At the same time, psychologists, social workers and other professionals were not attracted to the institutions because of their medical-nursing orientation. While programs were generally humane, the institutions remained grossly understaffed and primarily custodial in nature. There were, however, many persons for whom community services simply did not exist and admission to an institution continued to be inevitable.

Some of us became concerned about how to alter this situation. Obviously the requirement that the superintendent of an institution be a psychiatrist was no longer tenable. Even when pediatricians were also eligible, only one person was attracted to the job. It was evident that there would have to be significant changes if we were to meet direct care and professional staff vacancies that plagued institutional programs in the Province.

With the help of many people, the author introduced the concept of organizing facilities according to a unit system and establishing a training model to replace the traditional medical-nursing orientation. This idea coincided with, and was helped immensely by, the Federal-Provincial Conference on Mental Retardation called by the Minister of National Health and Welfare in September 1964. This Conference gave Ontario the opportunity it needed, not only to redirect its programs within the institutions, but to establish the base on which community programs have continued to develop over subsequent years.

The Minister of Health, Dr. Matthew B. Dymond, accepted the Ontario Conference Committee's recommendations for new Provincial programs, which became known as the Blueprint for Mental Retardation Programming in Ontario.[1] This certainly gave a major impetus to developments in the Province over the next 8 to 10 years.

Under this Blueprint, a Mental Retardation Services Branch was established within the Mental Health Division of the Ministry of Health, and this Ministry was designated as the coordinating Ministry for mental retardation services within the Government. An Interdepartmental Committee was established, with the Ontario Association for the Mentally Retarded as full-time members. This permitted a partnership to be established between the various departments of government and the association, which provided an opportunity for mutual understanding of the problems in the development of services and an improvement in their coordination across the Province.

Changes in Institutions

There were two major changes in the institutional component of care. The unit system[2] was introduced, and the Ministry of Education accepted responsibility for all educational programs.

Education

With the Ministry of Education taking over responsibility for the education of residents in facilities, there was a tremendous improvement in the level of teaching competence. Previously, with the exception of a few trained teachers committed to the teaching of retarded people, most teachers were recruited from the ward staff who held no teaching qualifications. These were either retrained or replaced by people fully qualified in special education. The improved budget allocation resulted in a standard comparable to the community school system, although physical facilities remained substandard. In Ontario, the right of all children to an education has not yet been achieved, so these programs now only encompass educable and trainable children from ages 5 to 21 years. There are 223 teachers in 193 classes, providing for 1,337 students within the provincially-operated facilities for the retarded.

The Unit System

The unit system, designed to replace the medical-nursing model, introduced the concept of grouping together retarded persons of both sexes into units where thir needs would be related to four major components.

- A Hospital Infirmary Unit for medical-nursing care for severely retarded, mentally handicapped, and chronically ill persons;
- An Educational Unit providing residential services and leisure-time programs for all children attending the recognized school program supplied by the Ministry of Education;
- An Activity unit for those persons not requiring nursing care under medical supervision, but not qualifying for admission into the school program;
- An Adult Training and Rehabilitation Unit for those able to take part in meaningful work or work-training programs.

This model now required that a nonmedically trained person replace the doctor as Unit Director. Similarly, a new kind of direct care personnel, the Residential Life Counsellor, would replace the nurse, nurse's aide and attendant.

Management expected these staff persons to fulfill more of a teacher-parent than a nursing care role. To achieve this change in orientation, a retraining program was established for the 2,500 direct care staff previously trained as nurse's aides and attendants and a two-year Mental Retardation Certificate Course was initiated for all new staff. The aim was to provide staff with the skills that would allow and encourage an increased amount of decision-making related to the needs of residents at direct care level. This two-year program is one of the most outstanding developments in the system. It has been constantly updated and revised to meet the changing needs of staff as programming for retarded people becomes more sophisticated and specialized. This staff training program is now being provided by seven community colleges in the Province and was used as the basis of the National Manpower Project developed by the National Institute on Mental Retardation.

The introduction of the unit system has resulted in improved staffing, both in numbers and in competence. It has also improved the opportunity for resident training with increased emphasis on individual needs and appropriate programs. New programs, however, came into effect last in the activity units where the most seriously and profoundly retarded ambulatory persons were grouped. It is in these units, and in the Hospital Unit, that behavior modification programming has had its greatest use, although token economy and other similar programs are used in all units.

The Mental Retardation Services Branch has encouraged the use of the Adaptive Behavior Scale, or modifications of that and other developmental scales, as a means of providing the Residential Counsellor with an assessment tool on which he can judge the level of functioning. With this information he can help in designing programs that will meet individual needs, and he thus becomes not only a contributor to the frequent conferences on his designated residents but a monitor of the functioning of that individual. In most instances he has a unit professional multidisciplinary resource team at his disposal to assist in the assessment and program development, as well as providing guidance in the Counsellor's ongoing management of the resident.

The introduction of the unit system brought a fear of lowered standards of medical and health services to residents, and at first there seemed to be such a reaction against doctors and nurses by the nonmedical Unit Directors and their staff that, in fact, there was a danger of this occurring. So a health service based on public health concepts was introduced under which prevention and early detection of disease and disability was encouraged. In this way, medical and nursing staff provided routine health examinations, vision and hearing examinations, tuberculosis control, immunization for infectious diseases and regular supervision of medication to all residents, particularly epileptics. As a result, the level of health care today is superior to that before reorganization.

Demand for admissions remained high and it was often difficult to determine who was most in need of the service and who should be admitted when a vacancy occurred, particularly when there was still considerable political pressure. It was decided to institute a preadmission rating scale modeled after one developed at the Woodlands Training School in British Columbia.[3]

Whenever an admission was recommended following an assessment at a clinic, a rating was made by the community Public Health Nurse. She was a neutral observer and a service contact in the home community we have found to be of particular value. The Rating Scale listed some 20 aspects of the individual, the family, the community, and the available services and each of these aspects was rated on a 0 to 5 scale. The total score provided an indication of those most in need of admission. The Rating Scale is an instrument the Public Health Nurse has found of help in the assessment of a newly referred child and family. It has also virtually ended political influence on admission. The politician has recognized the value of preadmission assessment and outpatient service rather than admission to an institution.

Changes in the Community

The Blueprint encouraged developments of community services by recommending the establishment of community residences. The Homes for Retarded Persons Act, still in effect in this Province, provided funding at the rate of $5,000 per bed for construction capital and 80 percent of approved operating costs to nonprofit organizations who would undertake the construction and operation of a community residence. It encouraged the development of sheltered workshops for the adult retarded. Although adequate financial support has not been provided, some 97 workshops have been developed over the years, which indicates the enthusiasm and sincerity of the voluntary movement in the Province.

During the past three years there has been a major move to the further development of community programs. Their goal is to phase down, although not necessarily phase out, the institutional component.

Organizational Change—Toward a Comprehensive System

This change was brought into clear focus by Mr. Walter Williston in his report prepared at the request of the Minister of Health, "Present

Arrangements for the Care and Supervision of Mentally Retarded Persons in Ontario."[4] Mr. Williston was called to examine the situation of two retarded persons who had been discharged from the Rideau Regional Hospital School in Smith Falls. Their condition had stimulated considerable controversy because of what was considered lack of adequate supervision by the institution. Mr. Williston examined not only the problem with these two residents, but the whole service system and he clearly delineated the deficiencies in organization, planning, and financial support. The report received strong endorsement from government, voluntary associations, and the community.

Williston found that six different Ministries were involved in the delivery of various aspects of the services, with little or no central coordination between them. Previously effective, the Interdepartmental Committee was no longer operative. The various Ministries had tended to drift into their own areas of service with increasing disregard for the activities of the others. Mr. Williston suggested a Ministry of the Handicapped as a method of forcing coordination but he also recognized that this could tend to segregate handicapped people from their peers. Fortunately, a major reorganization of the Provincial Government at this time established a number of Policy Secretariats under which Ministries with similar concerns were grouped together within a policy field for planning and coordination. The Ministries of Health, Education, Community and Social Services, and the Colleges and Universities were brought together under the Provincial Secretary for Social Development. This reorganization provided the central coordination Williston recommended but did not segregate handicapped people from their peers. It now became less possible for one Ministry to develop plans without the full knowledge and cooperation of the other Ministries in that policy field.

At this juncture, the Ontario Association for the Mentally Retarded submitted a brief to the Provincial Secretary for Social Development in which it suggested that mental retardation was more of a social than a medical problem. It recommended that all the diagnostic, assessment, and counselling services as well as the institutional facilities within the Ministry of Health be transferred to the Ministry of Community and Social Services.

Many of us within government organizations saw this as an opportunity to increase the coordination of services, since one Ministry would be responsible for planning and funding a wide spectrum of both community-based and institutional services. There was concern that government-operated services might again become isolated if they were left with a different Ministry. The government's acceptance of the recommendation for transfer gave concrete evidence of its willingness to accept a community focus for mental retardation services.

The transfer was successfully completed on schedule, with a relatively minor disruption of services. The Mental Retardation Services within the Ministry of Health supervised 12 facilities serving 6,500 retarded persons of all ages with a staff of 7,000 and an annual budget of $92 million. Such a large organization could only have been transferred because of a number of earlier changes.

- The change from a medical-nursing model to a training model. Training was acceptable to a Social Ministry where a hospital orientation would have been inappropriate.
- In 1967, budgeting of mental retardation services had been separated from that of psychiatric services, and at the same time each facility had been made more responsible for its own management. This greatly reduced dependence on the central organization of the Ministry of Health.
- In 1967, trained administrators were introduced to the facilities as the Chief Executive Officers, with the senior program person, previously the superintendent, reporting to them. This received considerable criticism at first, yet there is little doubt that operations are now more clearly defined in both program and administration. The facilities have cleaner and improved living conditions, residents' records are more precise and complete and the resident population has been reduced. Most of these developments have been a direct result of improved management, both centrally and in the facility.

Although these recent developments made the transfer possible, it would be foolish to suggest that there has not been tremendous anxiety on the part of staff. Certainly the medical staff, already threatened by the 1967 change to the training model, tended to see this as a further erosion of their role. Administrators saw themselves reporting to persons with no knowledge of the operation of large facilities, since never before had the Ministry been responsible for directly operating a service of this size and complexity.

A new organization has been established to develop and redirect programs for retarded people in the Ministry of Community and Social Services. The key group within the organization is the Mental Retardation Management Committee. This Committee, which is really a subcommittee of the Ministry's Management Committee, has control of the whole program, both community and institutional, with the exception of the formal educational programs which, of course, remain under the Ministry of Education. The Committee reviews all program plans and recommends major policy to the Ministry and to the Policy Secretariat. The membership includes the three people directly responsible for the services for the retarded as well as the Executive Director of Financial Services and the Assistant Deputy Ministers for Program Development and Program Delivery for the entire Ministry.

Program Delivery has two major components:

- The Community Services Development Program has been established to encourage the development of services within the community, to work closely with voluntary associations, and to encourage the integration of retardation services in the 19 District Offices of the Ministry with their services for all citizens.

At the district level, a Mental Retardation Coordinator is being appointed, and to assist him a reorientation working group drawn from representatives of concerned agencies and citizens. Together they will study existing services and make recommendations on additional services to meet the needs of retarded people now in the community as well as for those returning from the institution.

- The provincially owned facilities for the retarded fall under the direction of a General Manager. His job is to improve the services within the facilities as well as those offered by them to the community, to reorientate staff and the residents to the new community approach, and to reduce the facility population by 50 percent within 5 years.

Now for the first time Ontario has a stated policy of providing services to the retarded as close to their natural home as is possible. To achieve this, the Ontario Association for the Mentally Retarded and its 118 local associations are being asked to play the major role in developing the community services. Their record for service development over the past years in most communities equips them well for this responsibility and they are, in most instances, pleased to accept this role. Some locals and the Provincial Association, however, question whether they should continue this function or whether they should find another organization to handle the many administrative problems that will arise as these services become more widespread.

The Province is moving towards the establishment of regional governments, which now have responsibility to plan and recommend but do not operate health or social services. Perhaps in the near future an organization like the elected school boards, which report through the regional government, could be seen as the responsible agency in a manner similar to the Swedish counties. Should this or some other local nonprofit organization be formed to accept operating responsibilities, the voluntary group could have representation on these boards but their principal role would be to provide the watchdog, monitoring role and also the more personal services that will be increasingly necessary for retarded people living in the community.

Financial Implications

In Canada, mental health and mental retardation services provided in government-owned institutions received virtually no federal financial support under the Ministry of Health. With the transfer of responsibility to the Ministry of Community and Social Services, cost-sharing with the federal government under the Canada Assistance Plan is now possible. To qualify for support, the retarded adult must not have more than $1,500 in personal resources and must be in need of the services offered. A child is eligible for sharing if he is under the care of a Child Welfare authority. The residence in which the individual lives and receives services must be classified as Home for Special Care. Eligibility having been established, cash amounting to many millions of dollars has already come to the Province. There has been a commitment by government that new money will be expended on the new program thrust.

There has been some considerable concern because of the means test that must now be applied to retarded people before they can qualify for assistance. Actually, this has in practice proven to be of little concern, since the resources of each of the residents were known by the Public Trustee or by the facility staff. The question of charging now for a service previously free to all, however, has yet to be answered completely. Similary, children have not yet been included in the cost-sharing arrangements and therefore, costs are not levied against parents for any services their children receive in the institutional programs.

Although detailed planning for the future has in no way been completed, the major immediate thrusts can be stated as follows:

- Establish Mental Retardation District Coordinators in each of the 19 District Offices of the Ministry.
- Establish re-orientation working groups reporting to each of the District Mental Retardation Coordinators. Their responsibility will be to examine the existing services, plan for improved coordination and to advise the District Coordinator on the needs for additional service.
- Establish protective service workers to provide personal services and support to the retarded persons in the community. These will be case workers on the staff of each of the District Offices.
- Provide transportation costs for retarded persons unable to use regular travel for special needs.
- Establish additional Developmental Day Care Centers serving seriously and profoundly retarded children between the ages of 2 and 18.
- Provide Developmental Day Care Programs to school-aged children without cost to parents.
- Raise the capital grants to community residences from $5,000 per bed to 80 percent of approved costs. The Province already provides 80 percent of the operating costs. Adult residents are able to meet their 20 percent of the cost with funds from Family Benefit Allowances for disabled adults. In the case of children's residences, however, it is planned to provide 100 percent of operating costs.
- Raise the capital and operating grants to sheltered workshops to 80 percent of approved costs.
- Provide funds to local nonprofit groups to develop halfway houses to train institutional residents for community living. The staff and the program will be the responsibility of the mental retardation facility until such time as these can be turned over to community groups.
- Provide funds to increase staffing in the institutional facilities to meet the latest American Association on Mental Deficiency standards.
- Provide capital funding for modernizing living accommodations in some of the institutional facilities.

Plans provide for a reduction by half in the resident population of provincially owned facilities for the retarded. To achieve this and to provide for those persons now at home, of course, comprehensive service systems must be established. The unfolding of these plans, and the development of these community services, should be of great interest to those similarly involved in other jurisdictions.

Hopes are high that the community thrust will continue and that it will be effective in providing the comprehensive services we need. There is, however, one major overriding concern. With the

Numbers of Mentally Retarded Persons by Program and by Year

1. Population in Government operated residential treatment-training facilities: 1966, 7,292 persons in 5 facilities; 1969, 6,862 persons in 10 facilities; 1972, 6,487 persons in 11 facilities.

2. Population by age groups in above:

Age	1966	1969	1972
0–9	1,033	573	438
10–17	2,674	2,374	2,051
18–39	2,750	3,175	3,365
40+	835	740	633
Total	7,292	6,862	6,487

3. Mentally retarded population in Psychiatric Hospitals: 1966, 2,793; 1969, 2,635; 1972, 2,523.

4. Population of Private Board operated facilities for seriously mentally retarded and physically handicapped children: 1966, 215 in 2 facilities; 1969, 640 in 7 facilities; 1972, 640 in 7 facilities.

5. Total population of above facilities by year: 1966, 10,300; 1969, 10,137; 1972, 9,660.

present inflation and recession and with the threat of depression, will historical fears and financial concerns haunt the handicapped again? The protestations of us all must block the return to the overcrowded, understaffed, isolated and dehumanizing institutions of the past. Prevention, early detection with appropriate treatment, training, education and rehabilitation, all with dignity, must remain the right of all developmentally disabled people.

Program population statistics as of March 1974

1. Mentally retarded population by program as of March 1974 by child or adult.

	0–17	18+	Total
11 provincially operated mentally retarded facilities	2,800	3,920	6,720
3 mental retardation units in psychiatric hospitals	125	375	500
Mentally retarded persons not in special units in psychiatric hospitals	0	1,140	1,140
7 board operated facilities for seriously mentally retarded and physically handicapped	550	10	560
1 Board operated adult mental retardation facility	0	100	100
85 approved homes for provincial facilities	0	165	165
Total	3,475	5,710	9,185

2. Supervised and funded by ministry of health.

	Child	Adult	Total
Private nursing homes for children	445	0	445
Private nursing homes mostly adult	150	1,125	1,275
Private domicilary care	0	550	550
Total	595	1,675	2,270

3. Residential programs operated by:

	Child	Adult	Total
(a) Privately operated Government supervision and licensing only: 15 childrens' boarding homes	320	20	340
(b) Voluntary agency, mainly local association for mentally retarded supervision and funding by Government: 26 homes for retarded persons	125	440	565

4. Nonresidential services as of March 1974:

	Child	Adult	Total
(1) 73 day nurseries	875	0	875
(2) 97 sheltered workshops	0	3,405	3,045

	Students	Teachers
(3) Educational programs approximate statistics reported by schools as of June 1973:		
(a) In classes for trainable retarded	6,240	714
(b)(i) Educable retarded elementary school programs (average I.Q. estimated 65):		
In self contained classes	20,239	1,544
In integrated classes	8,814	947
Other programs	3,725	107
	32,778	2,598
(ii) Secondary school programs for educable retarded (average I.Q. estimated 75):		
In composite programs	21,099	1,320
In resource programs	632	4
	21,731	1,324
Total ministry of education programs	60,750	4,636

5. General population figures (estimated) for Province of Ontario. Statistics Canada: 1966, 6,961,000; 1969, 7,385,000; 1972, 7,825,000; 1974, 8,094,000.

Residential treatment and training facilities for mentally retarded as of Mar. 1974

(a) Owned and operated by ministry of health.

Location	Rated bed capacity	Beds set up	Numbers in residence	Persons on leave
Aurora	131	165	151	11
Cedar Springs	693	977	833	109
Cobourg	260	201	164	20
Edgar, A. O. C	270	270	200	65
Gravenhurst	297	297	281	13
London, CPRI	141	146	122	11
Orillia	1,412	1,719	1,544	125
Palmerston	204	226	200	23
Picton	600	392	358	21
Smiths Falls	1,128	1,585	1,519	101
Toronto S.P.C	34	34	23	...
Woodstock	728	715	604	19
M.R. unit:				
Kingston	142	157	133	10
Thunder Bay	184	226	218	9
Whitby	200	159	139	4
Total	6,424	7,269	6,489	541

(b) Operated by Private Board funded by ministry of health—schedule II.

Location	Rated bed capacity	Number in residence
Bathesda	122	121
Brantwood	91	91
Christopher Robin Home	52	51
Hogarth children's unit	108	105
Ongwanada children's unit	100	98
Plainfield Children's Home	73	73
Rygiel Home	101	98
Sunbeam Home	126	126
Total	773	763

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Biography

DONALD ZARFAS was born in Hamilton, Ontario in 1920 and obtained his primary education in Orillia, Ontario. He graduated in medicine from Queen's University in Kingston, Ontario in 1952. He studied psychiatry at the University of Toronto and received his specialist qualifications from the Royal College of Physicians and Surgeons of Canada. He was the founding superintendent of the Children's Psychiatric Research Institute, the director of the mental retardation services branch in the Ministry of Health for Ontario.

He is currently the professor of mental retardation in the departments of psychiatry and pediatrics at the University of Western Ontario. He has been a consultant to the World Health Organization, chairman of the professional advisory committee, Canadian Association for the Mentally Retarded, and is consultant to the Ministry of Community and Social Service for Ontario.

18. Encor, Nebraska

Brian Lensink

Introduction

The joining of the Federal government and the major national advocacy group (NARC) in a joint venture to seek exodus from the large public institutions is a dramatic turn around for the United States. During the past several years, increasing attention has been directed toward developing optimal alternative residential services for mentally retarded people.

All levels of government have joined consumer representatives in recognizing the right of retarded citizens to enjoy a normalized life which ensures continuing access to developmental opportunities. Accepting that the large institutional facilities and programs for retarded persons are, by and large, inadequate, isolated and misdirected, NARC, the President's Committee on Mental Retardation, and a number of Federal agencies–spearheaded by the Developmental Disabilities Office–have given national priority status to deinstitutionalization.[1,2]

It is evident that the old professional view that retarded citizens should be sent away form their home community "to be with their own kind" will go the way of the old tuberculosis sanatorium approach. In its place will be the rapidly developing systems of community-based services which, with active liaison from parents and advocates, will provide many exciting new opportunities for all mentally retarded persons. We will finally "turn the corner" away from the large public institutions as the major resource for serving our retarded citizens.

After assuming the ideological stance that services located in the community (readily accessible to mentally retarded citizens and their families) are the most reasonable, practical and humane approach to service delivery, the specifics of developing a service delivery system must be confronted. Although there are many administrative designs through which systems of community services for the mentally retarded might be offered, it may be helpful to examine one existing system. The Eastern Nebraska Community Office of Retardation (ENCOR) is part of a system which has been developing in Nebraska since 1969, when virtually no services or programs were available to mentally retarded persons in the community. This service system developed through the hard work and vision of a small group of parents and interested professionals intent on developing an alternative to institutional care.[3,4,5]

Today, six regional offices in Nebraska coordinate community services for mentally retarded citizens across the state. ENCOR is the oldest of the regional programs and has developed most of the service components necessary in a comprehensive system. It is designed to provide a continuum of services to meet the individual needs of mentally retarded citizens–from the mildly to the profoundly retarded, from infancy to old age and in population densities which range from rural to urban. The services are located in communities throughout the region and integrated into neighborhoods, industrial areas, and recreation areas. Depending on individual needs, educational, vocational, residential, and family support services are provided. Each program is designed to facilitate the retarded citizen's active movement into educational, employment, and independent living opportunities in the mainstream of his community.

ENCOR was designed to "bridge the gap" between needed and existing services, a challenge which has changed over the years, especially as services for the retarded have become available through generic agencies (e.g., public schools are serving more retarded children, generic agencies are including more retarded persons in their services, etc.). The services which have been developed are those which were not being offered by existing systems in the community. As existing systems expand their service outreach to handicapped citizens, ENCOR modifies the components in its system. Since maximum normalization of the retarded hinges upon their greater integration into the mainstream of our society, the system of services was designed to provide or secure any service or support which a mentally retarded person might need in order to live—with maximal social-vocational adjustment and personal dignity—in the community.

Ideology—The Pillars of the ENCOR System

As previously noted, the principle of normalization has strongly spurred the current renaissance of community-based service for mentally retarded citizens in our country.[6,7,8] Several key ideological principles, encompassed within an overall normalization philosophy, have shaped the way ENCOR services have developed. These major principles include the *developmental model*, *specialization*, *continuity*, *integration*, and *dispersal*. Directly flowing from these important principles are six practices which include *consumer participation*, *human dignity*, *cost benefit*, *systems flexibility*, *human scale programs*, and *community support systems*. These principles and practices are illustrated in Figure 1.

The five basic principles will be discussed individually and the six practices will be presented in the context of service descriptions later in this chapter.

The developmental model (see Figure 2) is a principle that strongly affects the direction in which a service system develops. Based on the developmental model, programs are designed to modify the rate and direction of client behavioral change. As a retarded citizen grows and develops, the system must allow more independence and less structured program alternatives.

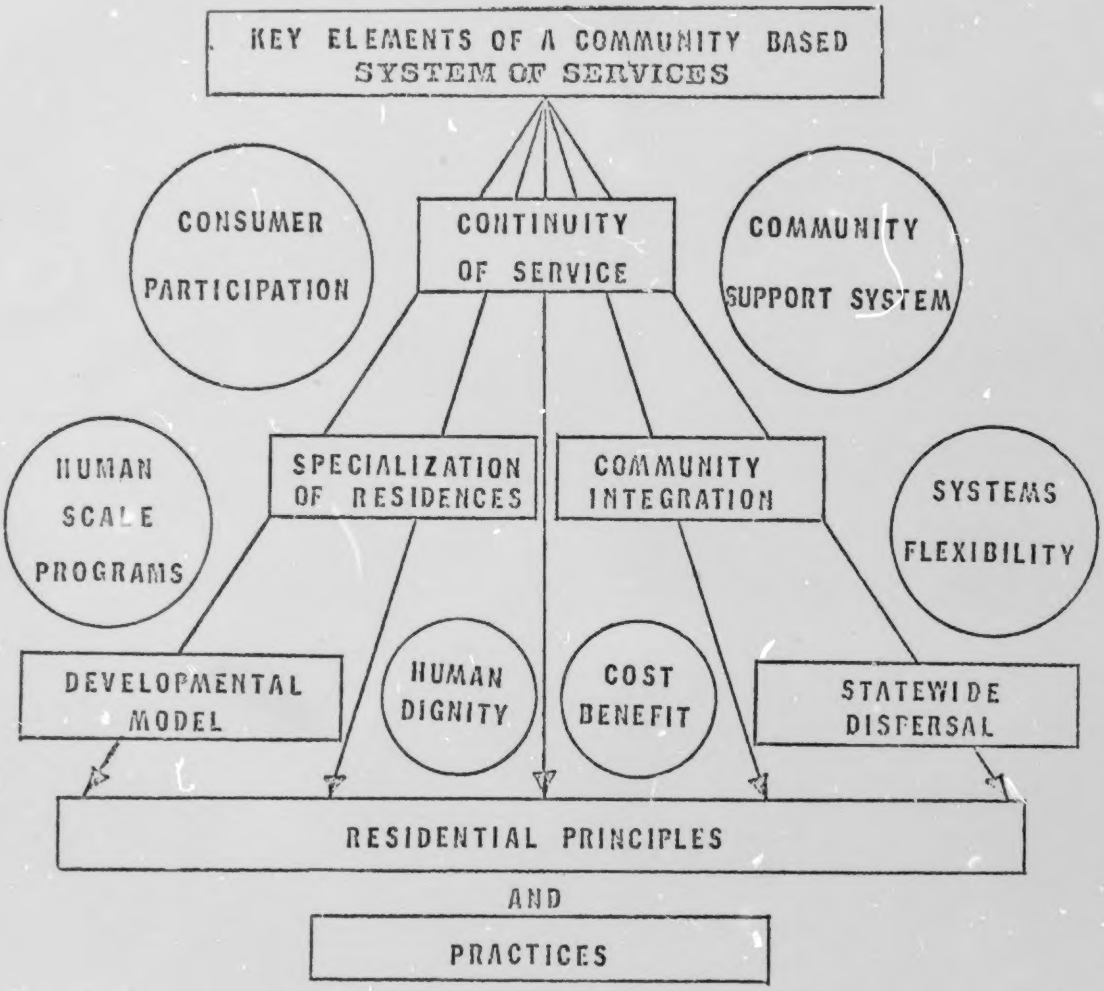

FIGURE 1

KEY ELEMENTS OF A SERVICE SYSTEM

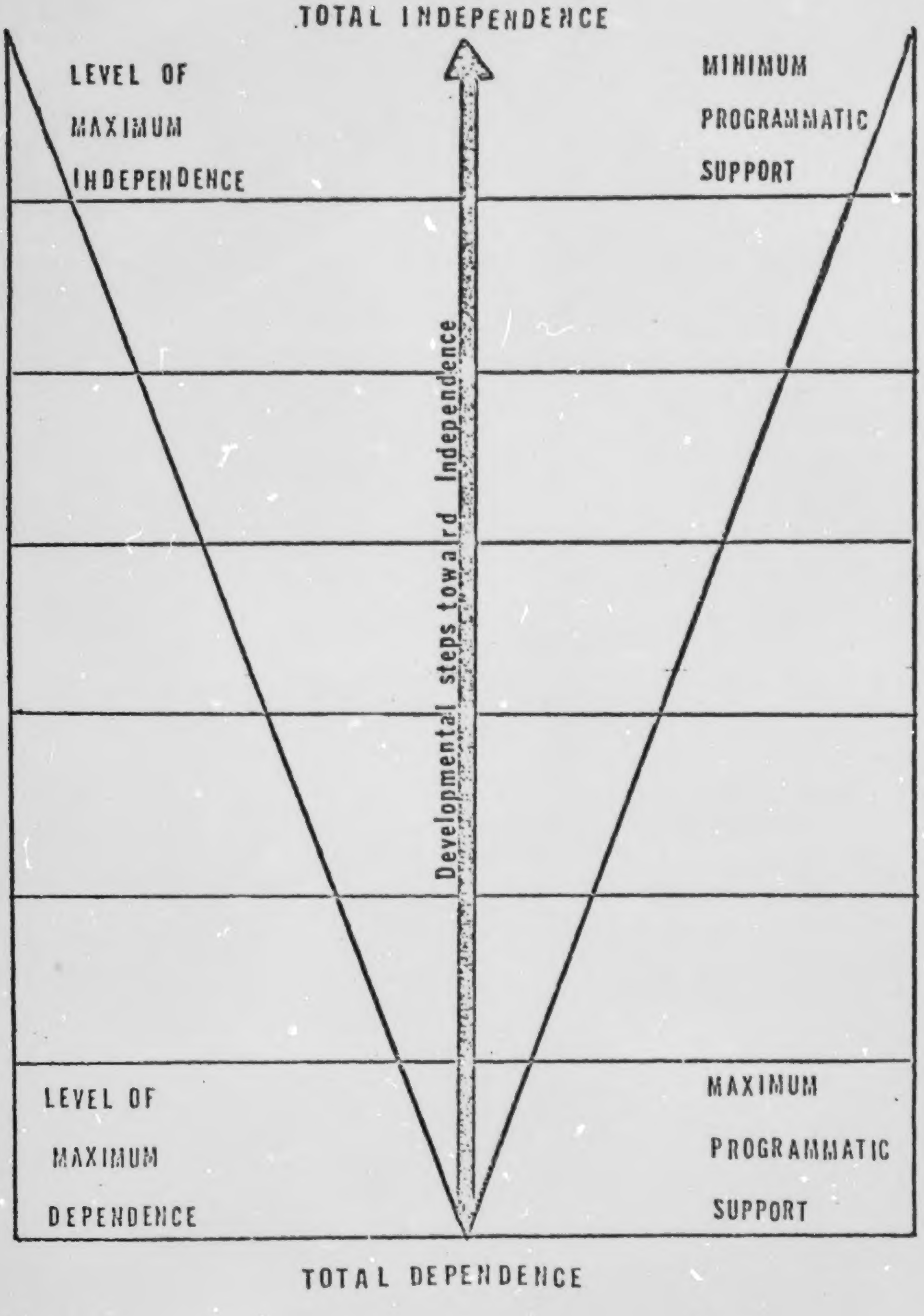
TOTAL INDEPENDENCE
LEVEL OF MAXIMUM INDEPENDENCE
MINIMUM PROGRAMMATIC SUPPORT
Developmental steps toward Independence
LEVEL OF MAXIMUM DEPENDENCE
MAXIMUM PROGRAMMATIC SUPPORT
TOTAL DEPENDENCE

FIGURE 2

DEVELOPMENTAL MODEL

The sincere belief that each retarded citizen is capable of learning is demonstrated through programs that prepare a retarded citizen for subsequent steps or goals in his individualized developmental plan. These programs are originally designed to facilitate growth, movement, and progress. The system then accommodates growth and development by providing (or by securing within the community) program options which take into account the individual's growth by providing less structure, more integration into the community, and more normalized conditions in which to learn, work and live.

Small *specialized* facilities and programs enable a system to provide services geared to meet the needs of the individual. For example, one residential setting cannot serve all clients, and it is inappropriate to design one facility (or one program) for serving the moderately retarded, the medically complex, profoundly retarded individual, as well as the mildly retarded person who needs only minimal supervision and guidance. On the contrary, programs can be specialized as to age appropriateness, degree of disability, need for structure, a prosthetic environment, etc. This is not to imply that persons with dissimilar handicaps are rigidly segregated, but rather that individual needs can and must be met within specialized programs. This principle is particularly important when considering community residential alternatives. Most people in our society, sleep, work, and spend leisure time in separate settings—so also should retarded citizens. A residence provides a home environment—a place to eat, sleep, and spend leisure time, relax with friends, entertain, keep one's possessions and receive telephone calls and mail. Children leave their residence during the day to attend public school or other educational programs. Adults leave their residence to participate in vocational training or to participate in work in the community. Some leisure-time activities take place in the home (as they do for all of us) but many take place in the community—in theaters, restaurants, community gymnasiums or parks. The division between home, work, and school is just as significant for the mentally retarded person as it is for other citizens in our society.

Providing a *continuity* of programs facilitates the growth and development of each mentally retarded persons receiving services, and is the primary objective of a progressive service system. Individual development is manifested by a person's movement from a highly structured educational, vocational, or residential environment to a less structured and more normalized setting within the community. A service system can accommodate such developmental movement by providing program options within developmental and residential continuums of service. For example, the residential continuum illustrated in Figure 3 ensures that the client who enters the system at the family living residence state of development has available to him the next step of an adult training residence as well as the availability of a number of such steps in the future.

The developmental continuum illustrated in Figure 4 assures the same service availability in the developmental and vocational areas of programming.

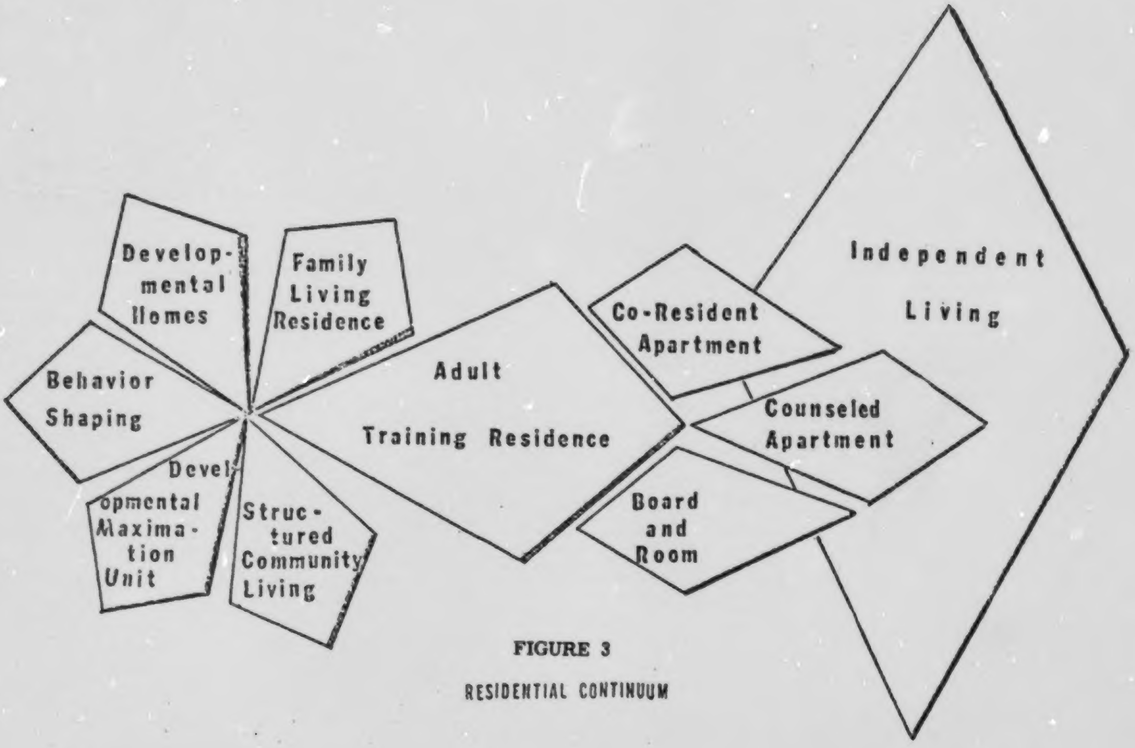

FIGURE 3

RESIDENTIAL CONTINUUM

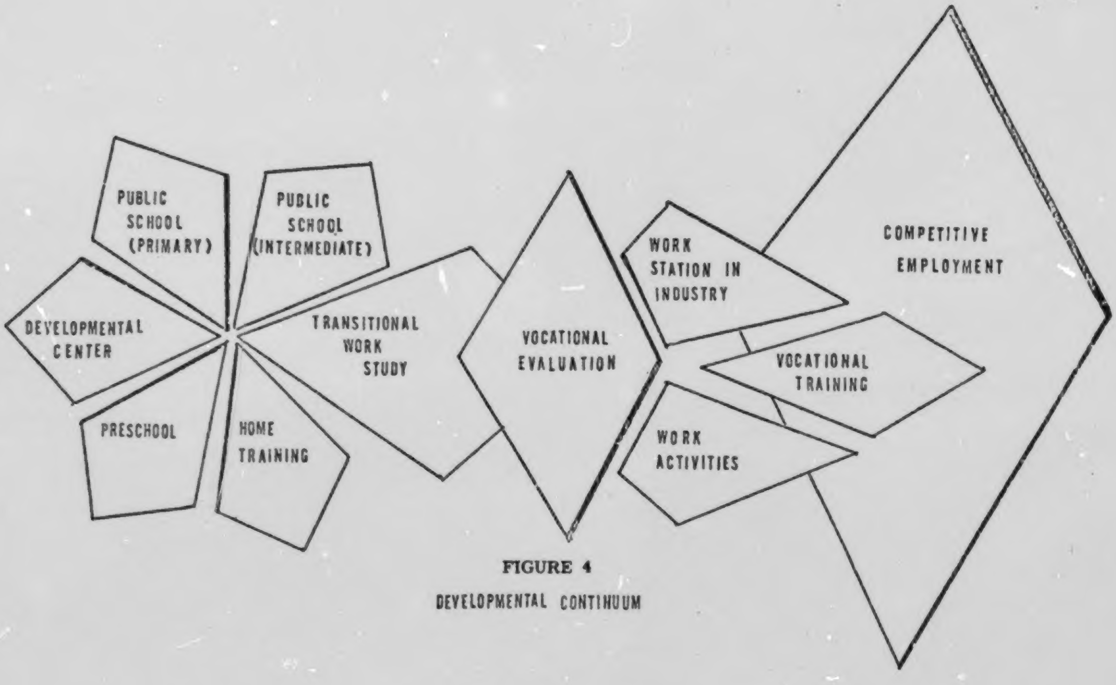

FIGURE 4

DEVELOPMENTAL CONTINUUM

This comprehensive system is continually evolving so that at no point in a person's life will services be denied because the system cannot provide the program or support necessary for that person's continued development. This continuity of service efforts permits retarded citizens, parents, and staff to see what is ahead of them as they work continuously on their developmental program.

Integration of retarded persons into the mainstream of society affords them the same rights and opportunities the rest of society enjoys. A service system can facilitate physical integration by locating residences in popular neighborhoods and in typical housing; by locating vocational training centers in industrial or commercial areas; by securing educational services in ways that are typical for the community; and by insuring that community resources (i.e., recreational, social, religious and medical) are available and accessible. Social integration can be maximized by securing opportunities for interaction between retarded and nonretarded citizens in the community. Seeking education for children in the same building or classrooms used by other children, securing work training for retarded adults with other workers in the community and providing a family living situation with a real family—are all means of facilitating social integration. In true physical and social integration, the community as well as the retarded citizen learns to live together.

Programs need to be *dispersed* across a state, across a region, within a city and even within a neighborhood. When a new program or facility is about to begin operation, consideration must be given to its location. A program must, of course, be readily accessible to clients and reasonably convenient for staff. Program facilities should be geographically dispersed throughout a region and two or three residences should not be established in the same neighborhood, because concentration of many facilities in the same immediate area could present a neighborhood with more retarded citizens than they might be willing to absorb. While dispersing programs, reasonable consideration must be given to the accessibility of vocational and developmental programs for those citizens living in the various residential facilities.

The preceding five principles must be actively considered in all administrative and program decision-making processes and be given high priority in the initiation and development of community-based systems for the mentally retarded.

Structure of the System

A wide variety of services is needed if we truly intend to provide a comprehensive program which adequately serves all mentally retarded citizens. To meet this challenge while implementing the principles and practices critical to an innovative system, four divisional thrusts were developed within the administrative structure of the service system (see Figure 5).

Service Components of Present
ENCOR Administrative Structure

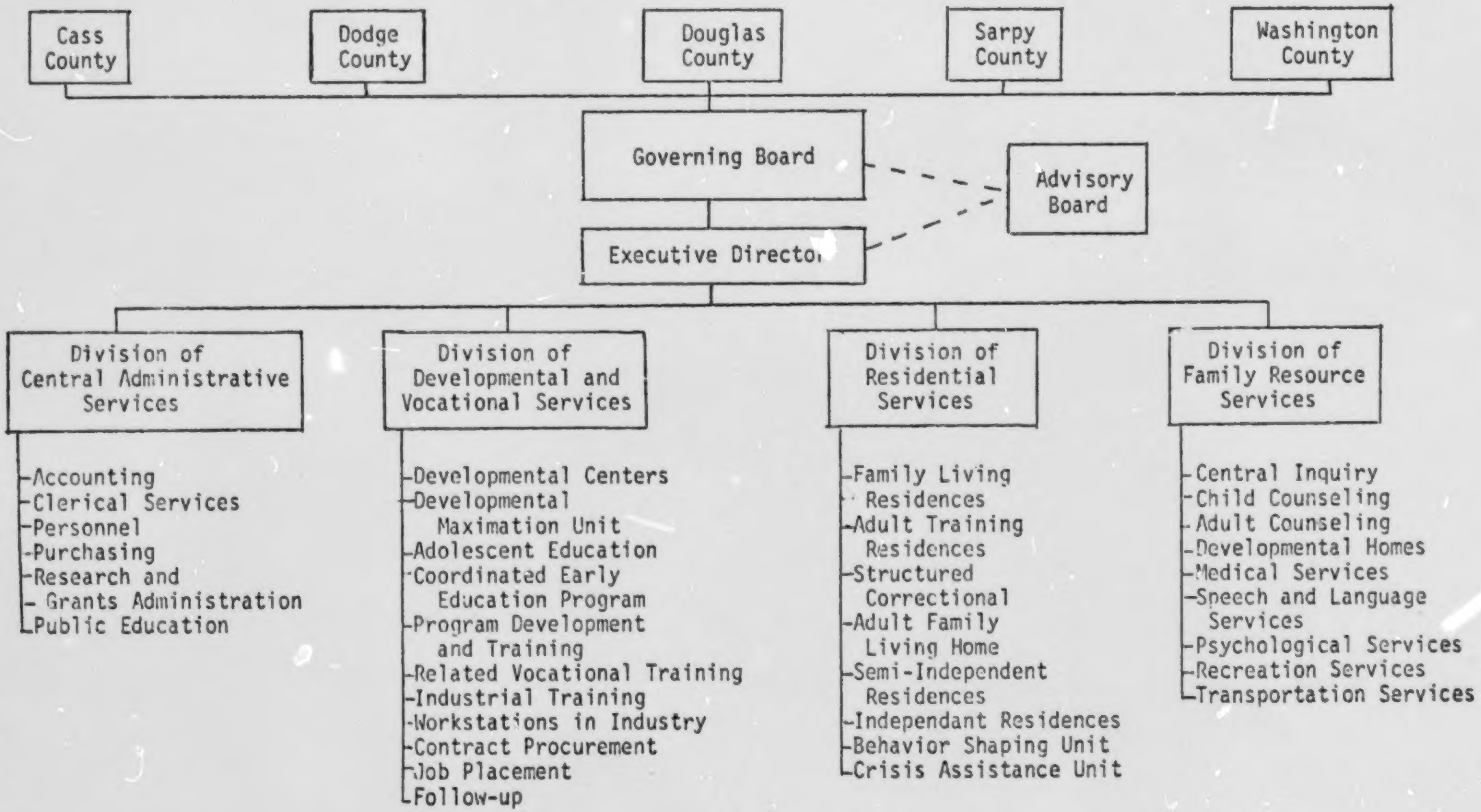

FIGURE 5

These four divisional thrusts represent a "putting it all together" approach to the administration of a comprehensive system of mental retardation services. Flexibility is of prime importance when discussing the implementation of this system of services. As needs, expertise, location, and cost-benefit considerations change, so will the administrative structure of the system. Interdependence between divisions is of prime importance in a workable system. No one division should be able to stand on its own without support and assistance from another division within the system. This important concept must be implemented if a true "system approach" to the problem of mental retardation is to be embraced. Repeatedly, one notes in the same community a series of independent vocational programs, day-care programs, family counselling services, recreation programs, and transportation systems. None of these individual entities, either in their singular thrust or in partial combinations with other components, provides truly comprehensive services for retarded citizens. Putting it all together so that each component is dependent upon other components within the system assures comprehensive services which are also coordinated.

Flexibility is also important when decisions must be made as to what services will and will not be provided by the system. As generic community services develop, the system must be flexible enough to let go of its efforts, and as new needs are identified, the system must be flexible enough to move into those areas of need.

In the following detailed description of service divisions, it must be remembered that programs and services are provided only when existing agencies are unable or unwilling to include mentally retarded citizens in their programs, and only for as long as it takes other agencies to meet their legal or moral responsibilities. Maximum use of existing services is accomplished as counsellors identify which of their clients' service needs may be met through existing services in the community. Clients and their families might require services in health care, diagnosis and evaluation, recreation, family counselling, family planning, or legal assistance. After identifying a need for generic services, the counsellor seeks out the appropriate community agency and assists the family througbout the application and follow-through procedures.

Some generic service agencies are routinely used as part of the community's informal network of services for the mentally retarded. For example, a children's evaluation and rehabilitation service component of the University Medical Center provides diagnosis and evaluation through pediatric, psychiatric and neurological staff, physical, occupational and speech therapists, psychologists, social workers and public health nurses to handicapped children under the age of 16. Most children entering the system are channelled through the diagnostic and evaluation services provided by this component of the University; consequently, duplicate services for diagnosis and evaluation have not been created.

In addition to this approach for securing services appropriate to the needs of the individual, the system stimulates greater community service to mentally retarded citizens through its involvement with a variety of other agencies. One example of this involvement began several years ago when recreation programs were provided for mentally retarded children in the facilities of a local YMCA. After much discussion with the YMCA, a contract prescribing their greater involvement was agreed upon by the two systems. The YMCA was paid for its expense in providing recreation programs for mentally retarded children and was also provided with training for staff and volunteers, "curriculum" plans for the program, and regular consultative services. During the second year of the contract period, the YMCA assumed one-half of the expense of providing this service and is now independently serving mentally retarded people—integrating them into their other recreation programs whenever possible.

Thus, through the use of existing programs, local duplication of services has been eliminated while Federal, State, and local moneys have been freed for the development of needed programs. At the same time, this has promoted the integration of retarded citizens into the mainstream of our society.

Division of Developmental and Vocational Services

Children classified by their school districts as "educable" mentally retarded and "trainable" mentally retarded participate in public school special education. Recent legislation in Nebraska guarantees all children between 5 and 16 years of age a "meaningful education program," placing the responsibility for insuring that all school age children receive educational services directly on the local school boards. School districts may directly provide education or contract for educational services. The developmental and educational services which are provided by the mental retardation service system are designed to serve those children not eligible for public school programs.

By October of 1976 (the deadline for school districts' mandatory compliance with this law), some of the children presently served in developmental and educational services will have been transferred into public shcool special education classrooms. The service system will continue to insist that as many children as possible be served in public schools. Some educational services will, however, continue to be provided by the service system. The system will continue to serve pre-school aged children and the more severely handicapped children in its programs, working to prepare them for movement into public school or other mainstream educational programs. This will be funded, however, by the local school district. In addition, ENCOR's support systems for mentally retarded youngsters and their families will remain viable, even if another system would someday assume full responsibility for the *direct* provision of all education services.

The Infant Program places a premium upon early identification of and intervention with very young retarded children. This new service provides day care in a community day care center to infants (ages 1 month to 24 months), focusing on cognitive, language, motor, and social adaptive development. Instruction in "developmental stimulation" is offered to interested parents at the day care center. For families who do not choose to place their infant in a center, in-home instruction is offered to the parent and child by a "mobile" teacher.

The Developmental Center program is provided to serve mentally retarded childen under 12 years of age who are not eligible for public school programs or other mainstream public (or private) educational programs because of their age or extent of their handicap. The children are served in developmental programs just long enough to prepare them for mainstream educational settings. This year-round program operates five days a week on a school day schedule, with extended hours offered to families needing day care services. The centers, geographically dispersed, serve approximately 25 children each. Whenever possible, existing structures (e.g., churches) adaptable for use as centers are utilized.

The objectives of the Developmental Center programs are focused on several general areas of educational need. Training in daily living skills such as eating, dressing and undressing, grooming, toileting and personal hygiene is offered to children according to their individual needs. Gross and fine motor development, perceptual and sensory discrimination, social skills, cooperative group interactions and speech and language development are all areas in which children may need assistance. The belief that each child has an individual rate of growth and needs highly personal attention is accompanied by the belief that there is always another step or goal for each student. Progress and success for these students, then, is the responsibility of the teaching staff.

A system of direct and continuous measurement of the children's performance allows teachers to maintain an accurate picture of each child's development. Teachers are involved in a system called "precision teaching," a measurement system that O. R. Lindsley and his students at the University of Kansas started developing in 1965.[9] The use of precision teaching brings accountability to the forefront and makes communication about a student's performance less subjective.[10]

The Adolescent Education program serves children between the ages of 13 and 17 who are not presently eligible for public school special education. Again, an individually tailored educational program is designed for each child, with special emphasis placed upon the development of prevocational skills. Many of these children will enter vocational training at age 17. The Adolescent Education training program allows an age-appropriate grouping and curriculum for teenagers preparing for adulthood.

The Coordinated Early Education Program places pre-school age children in early education programs in the community. A resource/consulting teacher (trained and employed by the service system), is placed with four or five young retarded children into an early education center in the community. The retarded children play and engage in learning activities with the other children in the center. The resource/consulting teacher manages several individualized educational projects (i.e., language development, self-care, motor development) with each child in an effort to provide specialized support within this normal, active preschool setting.

Two specialized educational programs—the Developmental Maximation Unit and the Behavior

Shaping Unit—share the goal of facilitating children's development so they might move into one of the less structured, more nomralized settings previously mentioned.

The Developmental Maximation Unit can serve severely and profoundly retarded children with multiple handicaps and complex medical problems in a residential/educational program. Most of the children participating in this program have some serious medical problems; the program seeks to minimize these physical problems so that the children can get on with learning. A consulting pediatrician extends needed medical care to the children and refers the children to appropriate specialists when necessary.

Although the unit operates in a remodeled wing of a hospital and has emergency access to medical staff and equipment, it does not resemble a medical environment. Draperies, children's furniture, brightly painted walls, carpeting, murals, stuffed animals and toys of all kinds help make the environment as home-like as possible for these children.

Educational priorities of this unit include motor control, the development of chewing, sucking and swallowing skills, the improvement of gross motor skills, and the acquisition of "tool skills" for language development. Many of these skills, however, are dependent upon the ability of the child to sit upright in a comfortable position. "Positioning therapy" is a program that places a multihandicapped child in the best functional sitting position with the support of individualized wooden chair inserts. This adapted "positioning chair" provides each child with positioned stability. Because of the structure of the adapted chair, the child's posture is stabilized and he is able to use his upper extremities to their fullest potential. All children tend to develop when these types of imaginative adjuncts to growth are provided.

The Behavior Shaping Unit serves severely retarded children whose maladaptive and/or primitive behaviors prevent them from participating in other programs within the service system of the community.[11] Operating according to the principles of applied behavior analysis in a program that is both educational and residential, the behavior shaping programs seek to provide intensive service to a maximum number of children in a minimum amount of time. Substituting appropriate social behaviors for maladaptive behaviors is important for the children's success. The major final objective of the Behavior Shaping Unit program is to teach the children the self-help skills and appropriate social skills needed for their entry into other developmental programs within the service system or into public school classrooms.

Vocational Service Centers (or workshops) provide a wide range of evaluation and training services within the community. A young person entering adulthood, regardless of his degree of retardation, leaves the world of the classroom and enters the world of work. Work is a crucial evaluation criterion in our society, and thus retarded adults must be fully assisted to develop their work skills and earn the accompanying societal respect and advantages that productive work brings. In vocational evaluation, the client is placed into the general shop setting. The physical setting is the same for all programs in the workshop and comprises a real work situation rather than a simulated one.

During an initial evaluation period, a new client is evaluated as to his potential for ultimate employment in a competitive community setting. At the end of the evaluation period, an individual summation is completed on the predicted potential of each trainee. This individual summation leads directly to a decision on the client's employment capability. It also outlines the suggested training program for the client, and specifies whether he will be placed in the vocational center's training program, or the center's Work Activities Center (long-term development program). The objectives for each and every trainee, whether in evaluation, work activities or training, are individualized and designed to bring about greater growth and development, whether their immediately resultant skills lead directly to employment or first to greater proficiency in skills such as money management or performance of a specific work task.

Training in vocational service centers takes place through paid performance of subcontract work obtained from local business and industry.

Work stations in industry also provide vocational services via minimally supervised employment in actual community industry or business. Under the supervision of a staff member, a crew of trainees completes subcontract work for the industry or business in which the work station is located. Work stations in industry can be operated at little cost to the service system. There is no need to pay rent, purchase equipment, or employ all the supportive staff necessary in a vocational services center. This arrangement also profits industry by eliminating the need to transport subcontract and short-term jobs outside their own shop. The integration of retarded and nonretarded citizens facilitated by the work station in industry is a most important feature of this type of vocational training.

The retarded worker is able to model other workers and is afforded the dignity of training and working as part of the community's work force. As retarded and nonretarded workers clock in, work, drink coffee, eat lunch, and produce together, normalization is readily witnessed.

Work stations have created new possibilities for the more severely handicapped adult. One new work station employee, five years ago determined to be forever in need of a sheltered setting, has competently mastered work tasks with every piece of machinery in the work station and recently completed his first job interview. Another work station is successfully training and placing in competitive employment men and women directly from the "work activities" designation in the workshop.

Independent Community Employment is the end result of the vocational services effort. At least 4 persons of the 200 adults served in vocational centers and work stations enter competitive employment each month. Creative approaches to the employment of retarded citizens must be considered and a direct effort must be undertaken to cultivate new employment options. The lack of employment opportunities has a tendency to "constipate" a system and has harmful effects on a staff which is successful in preparing the retarded citizen for a move.

The service system must address job development directly and forcefully and has done just that by having two full-time positions in this area. All businesses in the area must be contacted and recontacted on a regular continuing basis. The retarded citizen must be sold as a productive asset to the employer and not as the recipient of a goodhearted gesture toward the unfortunate. All retarded citizens can be an asset to an employer if the service system will invest in creative approaches to job development and placement. Individual employment opportunities will not be adequate alone and creative efforts such as two-for-one employment must be considered. This entails employing two marginally productive citizens to do the job of one—a possibility which allows many retarded citizens to work at their maximum ability in a competitive job environment.

Division of Residential Services: Children

All attempts should be made to provide families with the support they need to keep their mentally retarded son or daughter living at home until he or she reaches an age when it is appropriate to live away from the natural home. When circumstances prevent a child from remaining with his natural family, the child has a right to live in a setting similar to that in which other persons his age live. An array of residential services is designed to provide this opportunity (see Figure 3). These include foster and adoptive placements, small group residences in the community, special purpose residences, and semi-independent living arrangements for adults. The residential settings provided should be similar to other homes in the community.

A Developmental Home offers a long-term family living situation to a child so he can gain the sense of identity and security vital to realizing his full developmental potential. Placements with a family are made with the express objective that a child will remain in his "developmental home" until he reaches adulthood and is ready for more independence. A developmental home provides an environment which is very similar to that of other children his age living in the community. It can provide a mentally retarded child with more than a loving family, however, for developmental home parents are trained to extend the developmental center or public school program into the home environment. Coordinated with the school program, the home is responsible for carrying out the child's specific training programs as designated by his teacher.

Family Living Residences with a house-parent couple, provide a surrogate family for children between 3 and 15 years of age. The residences each offer six children an opportunity to experience family life as other children do, providing them with intimate contact and involvement with a small group of people. This family living experience is an important basis on which to begin developing skills in community living. A family living residence may be located in a house in the community, in a duplex, or perhaps in a modern apartment complex that has ready access to the community. During the day, children attend Developmental Centers or public school programs. After school, they may play with other children in the residence or with other children in the neighborhood.

Setting the table for the evening meal is a team effort. Dinner is a time for friendly family interaction around the table, but also provides an opportunity for helping children develop their self-feeding skills and, of course, table manners! Clearing the table and assisting in washing the dishes may also be a part of the regular operation. Evening schedules vary according to the age of the residents. Teenagers who attend public school special education classes may have homework to complete after dinner. Younger children may engage in games and special learning projects with staff members. Some evenings the family might watch television, listen to records, or just go for a walk.

On the weekends, some children visit their families. For the others, there is plenty of activity to keep them busy. In many homes, Saturday morning may be a time for putting the house in order. Children clean their rooms and help vacuuming, dusting, window washing, and laundry. Even though it might at times be easier for the staff to handle the cleaning quickly and efficiently themselves, everyone's participation is sought. By helping in these routine procedures, children can learn about what goes into running a house and how to perform some of the tasks involved, and view themselves as an essential part of the family unit.

As mentioned earlier, *Special Purpose Residences* such as the Behavior Shaping Unit and the Developmental Maximation Unit provide more specialized developmental/residential alternatives for some children. Children from the Behavior Shaping Unit or the Developmental Maximation Unit may leave these residential programs for their own homes, for a developmental home or, perhaps, for a family living residence.

The *Structured Correctional Residence* is geared to serve the mentally retarded adolescent whose actions have been brought to the attention of judicial authorities. In dealing with the adolescent offender, who is by no means a hardened criminal and is more likely to be perpetrator than an instigator of crime, a specialized program in the community is appropriate. A special residential unit, housing eight young persons and perhaps a houseparent couple, may operate under the direction of a person experienced and trained in the field of behavior management. The program in this residence is likely to be highly structured, with perhaps some degree of limitation imposed upon the freedom of the residents. The structured correctional residence will operate within the developmental continuum of services. The program in this residence will be designed to modify the behavior of the residents so they may participate in other, less restrictive, and more normalized programs in the community.

Adults

There are several residential options made available to the mentally retarded adult. These models provide the adult with a continuum of residential alternatives which prepare him for and allow him increasing degrees of independence.

Adult Training Residences are designed to prepare the mentally retarded adult to live someday in more independent situations. By sharing the responsibilities of caring for many of his own needs and the operation of the household, the resident has the opportunity to learn new skills and develop close relationships with a small group of friends. During the day, the adults living in a residence work in a vocational training program or competitively in the community.

An Adult Family Living Home is a residence in the community in which one to three mentally retarded adults live with a sponsoring family. These adults may be receiving training in a vocational services center or be competitively employed, but not yet ready to live independently and in need of some supervision and assistance. In order to qualify as a placement site, a family's home must be located in an area that provides easy accessibility to the rest of the community and must be similar to other homes in the neighborhood. The house must allow each resident privacy and facilitate comfortable interaction among everyone living there. The attitudes displayed by the family who has opened its home to retarded persons must be constructive, respectful, and appropriate to the age of the mentally retarded persons. The family must believe in the growth potential of the retarded persons and be willing to help them increase their independence and control over their own lives.

Residential staff members and clients who have lived together remain friends, even after a client is living independently. Social activities are sometimes shared and birthdays or other special occasions may be spent together. Even after a move into an *independent living* situation, a client may still call his counsellor when he needs assistance or advice. If the retarded adult experiences no difficulties in living independently, all formal and legal ties to the service system may be broken.

Crisis Assistance is provided to support families of the mentally retarded in their endeavor to keep their families intact. The first component of this service is a *Crisis Assistance Residence*—a home in the community with houseparents and other staff that allows parents temporarily to place their mentally retarded son or daughter in a home setting from which he or she can continue educational or vocational activities during the day. During this short separation, the family might take a much needed vacation or attend to the problem or situation at hand—perhaps the birth of a new baby, illness of a parent, or an out-of-state wedding. An alternative to the crisis assistance residence is a *Crisis Home* in the community; the agency can contract with families who are willing to have a retarded citizen stay in their home on a short-term basis (from one day to a month). Because only one person is placed in a crisis home at a time, close contact with members of the crisis home family is assured. With both types of crisis situations available, maximum flexibility of this service can be provided.

Division of Family Resource Services

This division administratively groups staff members who provide services to families, clients, and other service system programs. The staff includes counsellors, speech therapists, recreational specialists, nurses, psychologists, and psychometrists. Direct service programs do not employ their own teams of specialists, which allows a more cost-efficient use of professional services. Consolidation of these services into one division has the added advantage of allowing professionals and paraprofessionals in the same field to share ideas and experiences and to collaborate in innovative program development. All Family Resource Service staff members are assigned to family service offices dispersed throughout the region. These staff members use their assigned office as a base of operation which is conveniently near the persons they serve.

Centralized Inquiry facilitates entrance into the system of services. A client, a family, or a referring agency in the community has only to make one phone call to obtain information about entrance into the system. Basic information about a potential client needing services or assistance is taken through Centralized Inquiry and referred to either child counsellors or adult counsellors serving the geographical areas from which the call originates.

Child and Adult Counsellors assist clients and their families in seeking out and receiving other services in the community when appropriate, facilitate entry into the system, coordinate individual program plans for clients, provide goal-directed functions on a contractual basis, and provide follow-along services to clients who have left direct service programs. Once a counsellor has received the name of a potential client from Central Inquiry, a home visit is made to complete application procedures. If services are not appropriate for the inquiring citizen, the counsellor may provide assistance in seeking out and receiving other, more appropriate services in the community. If the counsellor does feel that services within the system are appropriate, he proceeds in assisting the client in obtaining the services.

The counsellors are responsible for coordinating an individual program plan for each client in their family service office area. This individual program plan spells out objectives and goals of the developmental services. The retarded citizen, parents, teachers or trainers, and the psychologist, recreation consultant, and speech therapist serving him, as well as staff from any other agency serving him, can all be involved in these program planning meetings. Long and short-term goals are described within a designated time frame and staff members responsible for each objective are identified. Three months later, the same group reviews the client's individual program plan, updating objectives as appropriate. The individualized plan is then reviewed half-yearly for each client. Any direct "counselling" services for clients in developmental, vocational or residential services are rendered on a contractual basis. Under this system, if a staff member from one of the direct service programs sees the need for special assistance which cannot be easily provided in the program, a request for that assistance is sent to the counselling supervisor for the geographical area in the form of a "contract request." The contract agreement describes counselling functions in goal-directed terms indicating that a counsellor who engages in a contract becomes responsible for reaching certain objectives with the client. Once a client has "graduated" from a direct service program, the counsellor becomes responsible for seeing that the client's needs are met. Once a client is successfully employed, living independently and has had no need for his counsellor's services, formal ties with the agency may be ended.

Medical Services must be provided in a comprehensive service system. The system employs two nurses who maintain contact with students in Developmental Centers and clients in residences, acting in a capacity similar to that of school nurses. The nurses provide simple medical attention, referring clients to physicians as necessary.

Eighteen physicians in the five-county region provide medical care as needed to the retarded citizens living in residences; the residence is interpreted as a family unit and the physician simply acts as a family doctor to the mentally retarded persons residing in the residence. Psychiatric consultation is provided as necessary through the services of local psychiatrists.

The system is also involved in the prevention of mental retardation. In an effort to prevent repeated occurrence of mental retardation in a family, counsellors make referrals to the genetic research and counselling component of the University Medical Center. A cooperative "phsyician and community education" program has been the effort of both the service system and the Association for Retarded Citizens. Information on mental retardation, its prevention, and local services has been placed in the offices and waiting rooms of physicians throughout the community. It is hoped that this effort will not only reduce the incidence of mental retardation, but also encourage early childhood intervention, thus preventing more serious future handicaps. Medical students and psychiatric interns receive practicum experience in the service system. Through educating future physicians about mental retardation and community service systems, early identification and appropriate referrals for educational intervention will be improved.

Speech and language specialists serve students in Developmental Centers and trainees in Vocational Service Centers. This staff has outlined a language lattice, indicating the ordered development of speech. Through seminars, these professionals have worked with other members of staff, teaching them skills they need in order to elicit language development. The lattice serves as a guide to all staff members in pinpointing objectives for speech projects.

The psychological services staff members evaluate clients when they enter the system. This staff also works closely with schools, school boards, school psychologists, and public school teachers in evaluating which developmental center students may realistically enter public school programs. Also working closely with Vocational Service Centers, the staff member aid in program development for prevocational trainees. Psychologists are also providing consultative service to residences in their development of individualized projects for clients.

Recreation services are available to any mentally retarded child or adult in the region, and are not dependent upon the individual's enrollment in the service system. Community recreation agencies are strongly encouraged by the staff to include the mentally retarded in their regular programs. Because of the support and encouragement to these community agencies, many children and adults are being integrated into leisure-time activities provided by generic agencies in their own neighborhood areas. Direct programming for children stresses physical and social development.

Transportation is provided to all retarded citizens who would not otherwise be able to attend their educational or vocational programs. All adults are expected to use public transportation if at all possible, and programs are designed for those who need training in how to use this public service. The importance of a good transportation system cannot be underestimated. Children and adults must leave their residences to go to school, workshops or employment and to maintain a normal rhythm of life. Also, transportation may be the key to service availability in more rural parts of a region. Special creative efforts must be made when looking at transportation for severely retarded, multiply-handicapped citizens.

The service system provides for the recruitment, screening, placement and evaluation of volunteers. Volunteers are used only to supplement the work of paid staff. These interested citizens are a great asset to embellishing the quality of services provided as well as allowing mentally retarded citizens in the community to form important friendships.

Division of Central Administration Services

The Central Administration Office deals with all administration and provides no direct services. Administrative services include personnel, purchasing, accounting, research, grant administration, public education, and centralized secretarial support. The offices of the directors of the four divisions within the service system are also included in Central Administration. Comprehensive and ongoing communication and planning between divisions is of utmost importance and can be facilitated in a centralized location. The administrative services are provided for the benefit of all service areas and each division is dependent upon Central Administration for all administrative support. Accordingly, Central Administration Services encourage divisional independency.

Consumer Involvement and Monitoring

In order to insure the continued viability and flexibility of the service system, there must be consumer involvement and monitoring activities at all levels. This effort must begin at the very highest administrative level by including consumers on the Governing Board of the service system. These individuals must have the ability to express their opinions and effect meaningful change within the system.

In addition to direct involvement on the governing board, the service system should develop an advisory committee made up representatively of consumers and citizens from across the service area. This advisory committee should review all planning and budgeting aspects of the agency and have the capability to make recommendations directly to the governing board and the agency director.

The ability for consumers to be continuous change-agents within a service system also implies some direct input at the client contact level. Therefore, each service or program within the system should develop an advisory committee or group which assures the mentally retarded citizen and/or his parents the opportunity to make recommendations on individual program considerations. These internal consumer involvement mechanisms will help to insure that the services provided continue to be those needed by the consumers.

However, internal mechanisms are not enough to insure viability and change within an agency. Parents of the mentally retarded citizens within the service area were responsible for getting the community-based system of services off the ground and consumer involvement in these services continues to play a vital external monitoring role. Through the local Associations for Retarded Citizens, groups of parents/consumers actively monitor the service system. Human and Legal Rights Task Force Committees make visits to programs, solicit information about programs from parents and clients, hear grievances and make recommendations to staff and ultimately, if necessary, to the governing board. Monitoring systems of various kinds are crucial to success and have a very direct relationship to the ongoing efforts of a system of community services.

ENCOR and the Challenge of Change

The ENCOR model was planned and implemented during a bubbling period of enthusiasm. This enthusiasm, coupled with deep commitment and persistent work, led to very rapid developments in services, in a major public education and information thrust, and in the corralling of the necessary legislative and financial components to fuel even more of the needed services.

The hopes of parents were extremely high as they recognized a firm basis for realistic anticipation that services would be available for their children—now and in the future. Indeed, the parents helped to decorate the first community-based facilities, established a policy guideline that of the clients in the residences, 50 percent would be from the institution, while 50 percent would be from the community, and did excellent early case findings through such mechanisms as neighborhood canvassing.

As the programs developed, both in quantity and quality, a number of roadblocks developed—roadblocks beyond those associated with administrative size and the well known communication barriers associated with growing organizations. When these roadblocks were first encountered there was a tendency to view them as transitory problems attributable to the difficulties of individual client needs, personality conflicts, etc. However, on reflection—then and now—it became clear that they had arisen because of limited foresight. This section is written in a spirit of sharing and aims to help the reader avoid similar problems.

As previously noted, the five major components of the "model" system of community-based services—which became reality via the establishment of ENCOR in the late sixties—were Developmental Centers, Vocational Centers, Family Resource Services, Residential Services and Central Administrative Services. (See Figure 6.) Ironically, there soon developed a series of major roadblocks in each of these five components which affected their potential contribution to the fulfillment of the initial promises of the ENCOR program. This was rather sobering—especially after the "high" experienced in the planning of ENCOR as "the answer" to Nebraska's terrible conditions; an answer which we believed would leapfrog the Scandinavian programs (which had often provided normalized institutions rather than truly community-based programs).

Embarking on a new path out of the ideological and programmatic wilderness of national-international models, and then inadvertently running into roadblocks we had created has prompted much soul-searching as to when, how, and why these roadblocks came into being. These experiences, and what we hope is their resolution, will now be explored.

FIGURE 6.—*Sample month's services* [1], *January 1975*

					Family resource services								
	Residential		Developmental	Vocational	CGS	AGS	Transportation		Recreation		Special services		Total
	C	A	C	A			C	A	C	A	C	A	
Unduplicated [2]	81	115	100	156	122	144	160	8	34	7	13	0	940
Duplicated [3]	81	115	139	243	122	144	336	148	67	134	271	233	2,033

[1] Categories Include:

Residential—Residences, alternative living units, developmental homes, developmental maximation unit-nighttime.

Developmental—Developmental services, coordinated early education program, adolescent education, developmental maximation unit-daytime.

Family Resource Services—Guidance (community clients only), recreation, psychologicals, speech and language, transportation, adult evening classes and motor development services.

C—Child

A—Adult

CGS—Child guidance services (community children only—not in residential, vocational, or developmental services).

AGS—Adult guidance services (community adults only).

Transportation

Recreation.

Special services such as speech, psychologicals, adult evening classes and motor development services.

[2] The client was counted only once using a "priority" system as follows: Residential; developmental/vocational; family resource services. Therefore, if someone received residential services as well as developmental services, he was counted under that category and not under the other 2.

[3] The client was counted for every service received.

NOTE.—Figure (6) above summarizes client participation in various types of services in a sample month. Movement through programs boosts the total figure to 1,200 persons (unduplicated count) who receive services during a 12 mo period.

The Developmental Centers

The establishment of the Developmental Center thrust of ENCOR was an outgrowth of (1) Opportunity Centers formerly operated by the local ARC; (2) an amalgamation of a number of small nursery schools with unstable futures; and (3) a direct response to the need for a new physical facility—since the original "Opportunity Center" was to be converted into a residential facility. The education wing of a church was obtained as a physical setting, teachers were hired, the parent advisory group was activated—and all seemed to be on a new path.

Within six months, the parent advisory group questioned whether the "new" Developmental Center was "really only giving baby-sitting services." The heterogeneity of level of retardation and chronological age (i.e., from 3 to 16 years!) was detrimental to individualized program needs and caused low teacher morale. Attempts to resolve these issues eventuated in parent-teacher squabbles (to the benefit of neither) and subtle overtures that some of the clients were "too old (or too retarded) really to learn anything here . . . ."

The rapid evolution of the Child Development Centers since this early period has been documented. What caused the rapid evolution? In brief, leadership by a very creative educator who came on board as the Director of the Division of Developmental Services coupled with an objective measuring technique (Precision Teaching) and a conscious attempt to bring the parents aboard as both surrogate teachers and advocates were the crucial ingredients of this dynamic change.

Today, ENCOR's Developmental Centers are attempting to place all of their children into generic educational programs. This move is helped by recent state legislation, fostered by parents and professionals in the ENCOR system, which mandates the right to education for all children. Accordingly, the future embraces the planned obsolescence of ENCOR's current five Developmental Centers: to three, then to two, one and out! Only within this timetable of planned change can ENCOR live up to its previous commitment to the principle of normalization.

Interestingly, the major roadblock towards this future goal is the old "fixation" of the educator: can you separate training from "real" education?

Since ENCOR has clearly demonstrated the effects of developmentally-oriented training for retarded children—and has aggressively obtained societal approval via a massive local public education program—it is pushing the educators forward.

Vocational Service Centers

The evolution of ENCOR's Vocational Service Centers was quite different from that of its Developmental Centers since they (1) were the first community-based service initiated for the retarded, (2) were directed by a well-trained and normalization-oriented director from their inception, and (3) have enjoyed a rather ample budget over the years. However, these historical precedents have not been a barrier to problems. The size of the centers, their physical locations (and interrelationship to clustering of other services), the types of job contracts obtained, and the very nature of the clientele served have all presented their share of problems.

For example, early on it was noted that other agencies energetically attempted to "dump" their "tough" clients into the ENCOR Vocational Centers all at one time. In the area of job contracts, a "near fatal" early decision was the obtainment of a hair curler assembly contract—an item that was easily assembled, fairly profitable, and available in abundance from a local factor. This particular contract became, unfortunately, the "standby" contract and since it was easy to obtain and complete began to diminish the early efforts to obtain a variety of contracts of varying complexity.

Roadblocks to the efficiency of the Vocational Centers remain today. The training centers need more business orientation in receiving, shipping, and inventory control; they have a continuing need for a broader variety of job contracts; they need time studies and task analyses to document productivity and would benefit from commensurate wage guidelines.

The road to the future lies with the work stations in industry and away from ENCOR's five Vocational Centers. Clearly, these stations are far more normalizing in their fiscal aspect and the dignity of the work setting provided for trainees—especially as they rub elbows in the real world of work! They promise real work for real pay in the real world, with supervisors who focus on moving the client, within six months to one year, into non-ENCOR sponsored work settings. Since the need for meaningful work is so basic to everyone, the future for ENCOR vocational thrust must remain flexible and innovative.

Residential Services

In the early days af ENCOR, it became obvious that residential services would be the Achilles heel of the new system because here parental, public, and professional opinions have traditionally differed so greatly. Indeed, the initial model of a residential setting for eight to ten clients was not new, having been tried on an international scale for many years. Yet, the type of clients serviced (i.e., severely retarded children and adults), the limited availability of residences and the interrelationship of the residential component to the complete ENCOR system of services for each client presented a new and monumental challenge.

It became clear, after one year of operation, that the residences were too structured for the needs of many clients—especially for those who were working and tended to view the residence as too constricting for their social-recreational interests.

There was a similar situation with the children who, though they functioned admirably in the group home, just did not need such a highly structured set of transactions. Interestingly, the length of stay and the high staffing ratio of the children's residential settings had initially been justified by the need to carry through the children's daily schedule of learning tasks at the Developmental Centers. Clarification of the carry-over needs into any family-like setting and the necessity for having children in truly home-like settings (with two to three other children rather than among eight to ten other children) prompted the move toward Alternate Living units.

Though there is currently great ferment in ENCOR's residential challenges and plans, it is clear that the future must embrace a strong commitment to supporting the child or adult in his primary family setting or in an enriched foster home setting. The future is a bit cloudy in the residential plans and their implementation because of the still unmet needs of a backlog of individuals who are still institutionalized or unserved in the community. Indeed, the need to catch up with currently unmet needs while simultaneously pushing forward toward new and more normalizing alternatives has made this dimension of ENCOR's programs a mind-boggling one!

Yet, its residential services are the very area in which ENCOR can shine, through programs for retarded persons of all ages and varying handicaps without the need for an institution or regional center as a backup. Residential programs serve as a vibrant backbone for the remainder of ENCOR's developmental-vocational-family service thrusts.

Family Resource Services

This division of ENCOR started to provide the social work functions of client identification, aid in entry into ENCOR-sponsored services, and general family counselling. It soon became the catchall for case-finding activities, family and individual counselling, coordination of transportation needs, medical, nursing and assessment services, initiation of recreational programs (in and out of ENCOR), and a variety of other activities which didn't seem to fit anywhere else. The very diversity of its challenges was a problem, but two roadblocks are more disturbing: (1) the division has no distinct identify and so "floated" as an always available crisis-oriented organization which never knew what to do after the individual or oganizational crisis was over, and (2) it increasingly took on the worst aspects of the usual welfare agency: staff from widely divergent training-experience backgrounds, no foci of activity, and precious little objective evidence that its efforts were consistently helpful. The identity crisis of this division was clearly apparent when staff roles vis-a-vis the other divisions of ENCOR were studied—was it their role to counsel a client in a residence, or was this the role of the residential staff? Were they really needed as a communication link with parents of a child in a Developmental Center? Did they have enough skills to do really effective counselling—individual or group?

This prompted much study of what the key role of this division could be in relation to the entire ENCOR system. It became clear that the role was one of coordination between and across all ENCOR service personnel—hence, the designation of the Client Advisor as an individual in the Family Resource Services division who takes full responsibility for obtaining and monitoring all ENCOR services for a client. The advisors assumed an active role in obtaining generic services from outside ENCOR rather than spawning the development of in-house services. This particular task has become increasingly effective in both streamlining the delivery of services and clarifying the professional identity of Family Resource Service personnel.

For example, the provision of medical services is arranged with a private medical practitioner who takes in the youngsters at a local residence as his patients—sees them in his office, makes house calls, hospitalizes in a private hospital, etc.—providing excellent normalized medical services which have been initiated and arranged by ENCOR Family Resource Service staff and then monitored by them.

More importantly, the Client Advisor approach has made one person in ENCOR responsible for obtaining, coordinating and monitoring all the service which any one client may need. The buck no longer passes between the Developmental Center staff, the houseparents, or other ENCOR staff. Increasingly, this mechanism will seek generic services in the societal mainstream rather than build a literal army of counsellors who attempt to "be all things to all people."

Flexibility was one of the practices described as a pillar of the ENCOR System. The system changes just described demonstrate this flexibility and its importance in maintaining an innovative, responsive, and relevant service system for the mentally retarded citizen of Eastern Nebraska.

Human Services and Mental Retardation—The Next Renaissance

As a community embraces the challenge of implementing a truly comprehensive service delivery system for mentally retarded citizens, they soon learn that the challenges confronting them spill over into many other human service endeavors. I believe that dehumanization of any group of people affects the ability of any other traditionally devalued group to shake the prejudices and roadblocks of the past.

Normalization through community-based services is an appropriate and effective approach to all human service delivery. Because human beings seldom easily or conveniently fit the categorical labels assigned them by "professionals," it is typically difficult to acquire services appropriate to the complex needs of many individuals. Besides these practical service problems, local elected officials and funding agencies become increasingly concerned with the virtual "maze" of services that seem to spring up overnight and with the tremendous duplication of effort which results. As a result, a multitude of additional challenges are placed on the doorstep of public officials and local service agencies and these challenges must be confronted.

The development of creative and innovative human service delivery systems must be looked at and planned concurrently with the establishment of community-based services for the mentally retarded. In order for these human service systems to have a positive impact on the lives of the mentally retarded citizens of our communities, it is of utmost importance that consumer groups and the National Association for Retarded Citizens embrace these new developing service delivery models so that appropriate underlying philosophies, like normalization, can be initiated to the best advantage of the mentally retarded citizen. Looked at positively, the human service system which combines a multitude of service delivery efforts can be of tremendous assistance and help to the ongoing development of the mentally retarded person.

A new human services delivery system is now being established in Eastern Nebraska. The system is known as the Eastern Nebraska Human Services Agency and embraces four major areas: mental retardation, youth, aging, and mental health services. All of these services areas are being developed under the same strong ideology which has been known as the pillar of the ENCOR system for the mentally retarded. All of these service areas have the same purpose: to "assist citizens in supporting themselves in the educational, vocational, residential, and other social environments available to the general public." With these four systems working together, citizens of Eastern Nebraska can receive more comprehensive solutions to their many and varying human service problems.

Labelling still remains one of the most serious problems for the mentally retarded citizen who is trying to "make it" in the community. This problem is, of course, common to all individuals who must be labelled and categorized if they are to get the service they need to live as independently as possible. The major challenge of the future is to allow people to receive the human services they need to thelp them. Forging human service delivery systems which work to solve individual problems instead of focusing on categories of people is the challenge of the future. ENCOR is now being consolidated into the Eastern Nebraska Human Services Agency in order to pioneer a futuristic approach to solving more completely the human service needs of mentally retarded citizens. ENCOR is again changing the pattern of service delivery for the mentally retarded citizens of Eastern Nebraska.

Conclusion

We have examined the development and current structure of one existing comprehensive service system for the mentally retarded citizen. This successful system was built on the normalization philosophy and is underpinned by five major principles: the developmental model, specialization, continuity, integration, and dispersal. The practices which flow from these principles include consumer participation, human dignity, cost benefit, systems flexibility, human scale programs, and community support systems, and must enter all decision making considerations of the system. The structure of the service system was based on these dynamic considerations. Four divisions cooperatively provide the continuum of services needed for the retarded.

However, a service system must not become statisfied once it has developed its basic structure. It must try to meet the challenge of change to remain innovative in serving the ever-changing needs of retarded citizens. As society take on more responsibility within its normal community systems, the special service system for the retarded must be willing to give up its efforts, to the advantage of the retarded citizens. Change is difficult and painful and often resisted by a service delivery system which is afraid to allow itself to develop, to diminish or to grow as the needs of citizens dictate. In order to continue innovative development and assure that the programs meet the needs of the retarded citizens, consumers must be allowed direct input into all levels of the service system—from governing board to individual programs and services. This input is not enough, however, and local associations for retarded citizens must establish monitoring efforts to provide an external evaluation of the service system on an ongoing basis. These efforts of implementation and systems management are the challenges of today.

The challenges of tomorrow center around the continued advocacy of mental retardation programs as they evolve into the new and innovative structure of the human services agency. The challenge is that of truly eliminating labels and allowing retarded citizens the dignity of interacting with all others.

In the future, through the efforts of community-based systems of human services, people will perceive and accept mentally retarded citizens as fellow human beings who need and can benefit from developmental stimulation and education within normal community education systems. In fact, a complete network of specialized services and programs which will provide continuity in the life of the retarded citizen will be integrated into the mainstream of our community services structure. Further, similar systems of service will be intergrated into communities across the state and across the country. The mentally retarded and their consumer advocates will demand and obtain equal rights for all retarded citizens and will force states to provide services which accord human dignity and which are cost-beneficial. This will mean that the day of the large congregate care institution will be gone forever—replaced by the true integration of retarded citizens into our society. At this point, all handicapped citizens will enjoy dignity and respect and our society will be accepting and caring. It would appear that no more challenges would exist under these circumstances.

What, then, are the major challenges when internal change agentry, efficiency, and a sufficient quantity of services for the retarded exist within our society? The challenge will be quality control, and this challenge will rest with the consumer movement, which must develop continuously with progressive service systems. Effective models and systems for consumer monitoring and advocacy must be developed in order to insure and maintain a life of dignity and respect for our fellow retarded citizens in the years to come.

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Biography

BRIAN LENSINK was born in Minneapolis, Minnesota in 1946 and received his BS degree from the University of Minnesota and his MS degree from the University of Nebraska at Omaha. He worked for the Greater Omaha Association for Retarded Children from 1968 to 1970, at which time he became director of the Eastern Nebraska Community Office of Retardation (ENCOR). In 1972, he was the recipient of the Rosemary S. Dybwad International Award and toured and studied community based mental retardation services in Sweden.

Presently, he is director of the Eastern Nebraska Human Services Agency, which is responsible for mental health, youth, aging and mental retardation programs in Eastern Nebraska.

19. Wessex, England

Albert Kushlick

General Background

Services for mentally handicapped people in Britain are the responsiblity of local and central Government. Education and training facilities are provided by local education authorities and social service departments respectively, with money from a general fund raised by local property taxes backed by central Government grants. Social service departments also provide a tiny component of residential care, mostly in the form of hostels. The bulk of residential care, however, is at present provided by the National Health Service in specialist hospitals for mentally handicapped people, which are staffed by nurses and nursing assistants, backed by doctors and other professionals. These hospitals were until 1974 the responsibility of 15 Regional Hospital Boards which had responsibility for all hospitals in the country.

In 1974, the boundaries and responsibilities of both health and local authorities were redefined. Responsibility for all health care now lies with a three-tier administration of regional, area, and district Health Authorities. Local authorities have lost their previous responsibility for community medicine, and in addition their boundaries have been redrawn so that they now cover the same ground as the new Area Health Authorities.

Policy for services for mentally handicapped people has been laid down in the form of guidelines from central Government. However, the evidence of varying patterns of care provided by both local authorities and regional hospital boards in different parts of the country shows that these policy guidelines have not been followed closely and the service cannot be considered homogeneous. In 1971, the Government produced a policy document on the development of services to mentally handicapped people, the first since the war and the first ever to give some indication of how services should look 20 years ahead. *Better Services for the Mentally Handicapped*[1] set the goal of reducing the number of people for whom the hospitals were reponsible from about 59,500 to about 33,400 over the next couple of decades, with an increase in local residential care, provided by local authorities, from under 6,750 places in 1969 to 42,700 places; local authorities were also to provide the educational and training places to back this residential service. This swing of responsibility for residential care was to be achieved by close cooperation between health and local authorities.

The local authorities were to provide for the more able residents, while the hospital authorities were to retain responsibility for the more severely disabled people with disruptive behavior. (The Wessex survey had shown that 50 percent of children in existing hospitals were continent, ambulant, and had no severe behavior disorders, or were ambulant and had no behavior disorder but were severely incontinent. It had also shown that 50 percent of severely retarded adults (IQ of under fifty) in hospital were continent, ambulant, had no severe behavior disorders, and were able to feed, wash and dress themselves without any help. This proportion was, of course, much higher among mildly retarded residents.[2] See Table 1. These findings were confirmed later in a national survey conducted by the Department of Health and Social Security.[3]

Health authorities were not to add to hospitals with over 500 beds, although new units of no more than 200 beds could be provided to serve total populations of not more than 250,000. Regional Authorities were also, however, encouraged to provide small units, homely in character and preferably sited in residential areas, with living accomodation and social activities very similar to those provided in local authority homes. As an immediate measure, hospitals were asked to "align" their hospitals—i.e., to bring together in one hospital those people whose families lived in the hospital catchment area—and to "sectorize" their wards—i.e., to bring together in one ward or series of wards in them all the people from a smaller part of the total catchment area, to make collaboration with local authority personnel working with handicapped easier and to promote

TABLE I.—*Wessex survey: grade, social or physical incapacity, and place of care*

[Rates per 100,000 total population [1]]

Age and grade	Place of care	NA	Incapacity All SB	Incapacity SI	Incapacity CAN	Total
Children:						
SSN	NI	4	4	2	20	30
	I	5	5	3	5	18
MSN	NI	1	1	1	7	9
	I		1		1	2
Adults:						
SSN	NI	2	2	1	45	50
	I	6	14	6	53	80
MSN	NI	1			69	75
	I	2	4	1	45	53

[1] Totals include cases where incapacity is not known.

Key.

I	Institution
NI	At home
SSN	IQ under 50
MSN	IQ 50+
NA	Nonambulant.
All SB	Ambulant but all have severe behaviour disorders.
SI	Ambulant, without severe behaviour disorders but severely incontinent.
CAN	Continent, ambulant, and not severely behaviour disordered.

Source: A. Kushlick and G. Cox (7).

continuity of care between hospital and extra-hospital facilities.

The extent to which the new policies are being followed also varies considerably. For example, by the middle of 1974 only 5 out of 15 Regional Hospital Boards had produced the joint 10-year development plans with their local authorities although these had been required by the Department of Health and Social Services.

Wessex

This last approach to decentralizing institutional care had already been launched some five years earlier by the Wessex Regional Hospital Board, using information collected by their research unit. It is the most advanced attempt in Britain to find ways in which the hospital service can contribute to a new, locally-based residential service for mentally handicapped people.

The Wessex Regional Hospital Board was set up in 1959 to take responsibility for all hospital services to a population of around 2 million people in a part of the South and West of England whose hopsitals had previously come under the Southwest Metropolitan Regional Hospital Board. This is an area whose two largest towns—Portsmouth and Southampton—have populations of around 200,000 people each. These form part of a virtually continuous urban development along the South Coast of Hampshire and East Dorset. Most of the rest of the population is centered in and around three smaller towns and much of the remainder of the region is rural and sparsely populated.

In 1974, the Wessex Regional Hospital Board became the Wessex Regional Health Authority, with new responsibility for a wider area and for general practitioner and community health services to go with the change of name. Its boundaries are now the same as the local authority boundaries of Hampshire, Wilshire, Dorset and the Isle of Wight.

The Experiment

The creation of the Wessex Regional Hospital Board had a considerable effect on hospital services for the mentally handicapped.[4,5] The region had in 1964 three traditional hospitals and satellites, with about 813,420 and 200 beds; like other parts of the country, it was trying to cope with overcrowding in existing facilities and a growing waiting list for places. These problems became more serious as soon as the new authority was created, for a number of mentally handicapped people in the region had in the past gone to hospitals outside its new boundaries. Although there was no pressure on the Board to "bring them home," their places could no longer be taken by other Wessex people as they died or were discharged.

It became apparent that Wessex needed more hospital beds. Professor Jack Tizard of the Institute of Education at London University advised that it should find out its needs more precisely through a prevalence survey, and this was launched, under my direction, in 1963. By 1966, it had become apparent that Wessex needed 450 new hospital places merely to meet continuing demands from a growing population—the figure being a compromise between the then Ministry of Health norm of 1.3 places for every 1,000 population and the Board's own resources—a figure of 1.1 places per 1,000 population. This increase in provision would not relieve overcrowding or unsatisfactory conditions in existing Wessex hospitals. The question was whether to provide these places by building up the two larger existing hospitals, by providing a new hospital, by providing two smaller new hospitals, or by providing small hospital units throughout the Region to meet local needs.

The working party set up by the Board to consider the problem opted for the last pattern. It already had preliminary results of its survey which suggested that a high proportion of people living in existing hospitals could equally well live in small local units; it had looked at the differences in standards of care between existing hostels and hospitals; it had noted that local authorities were developing community residential and training programs; it took account of developing public demands that mentally handicapped people in hospitals should not be cut off from ordinary society and from facilities available locally for all citizens; it saw the advantage to be gained from closer integration of all services to mentally handicapped people so that hospital provision became one component of a range of facilities available locally to deliver care and not a functionally and geographically separate facility; and it saw the advantages of regular assessment of the individual handicapped person by those who care directly for him. The Board accepted its recommendations.[6]

This meant that 450 places, built and administered by the hospital authority, had to be provided to serve local populations, 150 places for children and 300 for adults. These plans were considerably cut and existing hospitals were expanded to provide part of the deficit. Existing hospitals were enlarged in an attempt to relieve overcrowding. The Wessex hospitals in 1973 had 885,480 and 453 beds respectively and many of these are still 'overcrowded' by any standard. Over the same period a new form of service was developed. A children's hostel was opened in Southampton in 1970 and there are now 4 others; each has about 25 places and attempts are made to reserve some of them for short-term care. The new children's facilities now serve a population of 600,000 out of the total Region's population of 2.7 million. The adult unit contains all of the most profoundly handicapped and behavior disordered adults from a total population of about 50,000. The first 25-place adult hostel opened in 1972.

The Research Design

The Wessex research has been carried out since 1963 with grants from the Department of Health and Social Security and the Medical Research Council. Our work has now expanded to include all residential services to mentally handicapped people and recently to take in the care of the elderly. The aim is: "To refine, develop, and apply general methods of evaluating the effectiveness of different practices of health and social service care for the mentally handicapped and for the elderly."

We have defined a six-stage cycle of research and development for putting this aim into action. The first stage involves the definition of and collection of epidemiological data on the target population within a total population of defined size and demographic characteristics. Data include prevalence, behavioral characteristics, place of residence, and clinical conditions of the target population, and the types of specialized professional or voluntary people who are in touch with them.

On the basis of this sort of information, Stage Two draws up suggestions for services which are likely to be more effective than those which exist at the moment.

These alternative services are designed and measurable criteria of comparative effectiveness and feasibility are established: This is Stage Three.

During Stages Four and Five, data are collected and interpreted to identify the comparative effectiveness of the new and existing services; this includes a comparison of client "progress," family problems and experiences with the service, of "quality of care," of "administrative problems."

In Stage Six, all this is drawn together, with recommendations to make services more effective in future. The cycle is then ready to start again. The Wessex work in mental handicap has now reached Stages Four and Five.[7,8]

Stage One: Who and Where Are the Mentally Handicapped People?

We have tried since 1963, when our work first started, to find out how many people are categorized "mentally handicapped" at any time in a population of a given size and demographic characteristics. We have described the ranges of disability among the people identified—inability to walk at all with help, ability to walk with help, inability to feed, wash, and dress oneself, and inability to read, write, or to talk in sentences. We have measured the ranges of difficult, disruptive, or potentially dangerous behavior—like overactivity, physically agressive behavior, destruction of clothes or furniture, attention-seeking and self-injury. We have descirbed the clinical conditions associated with mental handicap. We have also described how the people who have been identified are being cared for.[9]

We can also compare for a total population of 400,000 the personnel resources available to mentally retarded people with the characteristics described from populations of defined size.[10] Table 2 presents the relevant data both for the mentally retarded who live at home and for those who live in hospitals for the retarded. The data on resources for hospitals for the retarded have been chosen from the 14 hospitals with the lowest nurse-patient ratio ('low') in England and Wales. It can be seen that patients in 'low' hospitals have access to very sparse resources indeed. These hospitals have been specially selected for comparison because they include the largest and most prestigious hospitals in England and Wales and because even in the best staffed hospitals, therapeutic resources are scarce. The extent of resources available to citizens including the retarded outside of these hospitals is also shown. The present siting of large hospitals for the retarded makes it extremely difficult to deliver

TABLE 2.—*Resources and clients of "Low" hospitals for the mentally retarded compared with resources and clients outside such a hospital. Total population served, 400,000*

Within 'Low' hospitals for the mentally retarded	Number		Outside hospitals for the mentally retarded	Number	
Consultant: Subnormality	1		Consultants only:		
			Paediatrics	2. 24	3. 58
			Child psychiatrists	1. 34	
			General physicians	7. 2	15. 12
			General psychiatrists	6. 36	
			Geriatrics	1. 56	
Other grades: Subnormality	1. 39		Physical medicine	1. 12	
			Orthopaedic	4. 00	
			Ophthalmology	2. 76	
			E.N.T	2. 64	
			Pathology	[1] 4. 8	
			L.H.A. doctors	21. 2	
			General practitioners	160	
Psychologist	0. 45		Education psychologist	4	
Social worker	0. 33		L.H.A.—M.H.S.W	12–20	48. 74
			Other	20–28	
			Child care officers	26	
			Home helps	252–312	
Therapist	2. 0		Therapists (hosp.):		
			Physio	35. 4	
			O.T	11. 8	
			Speech	1. 15	
			Therapists L.H.A.:		
			Physio	0. 4	
			O.T	0. 57	
			Speech		
Industrial therapists	1. 89		Industrial therapists	15. 7	
Teachers	4. 22		Teachers (J.T.C.)	20. 4	
Nurses:					
Qualified	12. 3		Home nurses	72–80	
Unqualified	19. 6		Health visitors	48–64	
Residents in mental subnormality hospital: [1]			Subjects at home: [1]		
S.S.N. children	80	600	S.S.N. children	[2]320	820
S.S.N. adults	320		S.S.N. adults	200	
M.S.N. adults	200		M.S.N. adults	300	

[1] Minimums.

[2] This includes 120 children not known to local health authority mental health department.

these "community" resources to the retarded in these hospitals.

The data on mentally handicapped people in Wessex in the original survey constitute the core of a register which has been maintained for 11 years.[11,12,13] It draws its information from many local health and social service sources. Errors arise when registers are maintained over long periods, and at the last check, methods of collecting have been shown almost completely reliable for hospitals—97 percent of cases were correctly shown to be in a Wessex hospital and 90 percent in the correct hospital. They are rather less reliable in establishing who is receiving training—84 percent correct—and still less in collecting information on special schools—53 percent correct. The methods of collecting information are now being revised. The uses to which it is put are also developing. A recent study, for instance, looked in detail at people identified by staff as presenting seriously disruptive behavior; incidents involving emergency sedation, restraint, or seclusion were recorded over three months.[14] This information will be used to inform and monitor policies for the development of security or intensive care units.

Stages Two and Three: Action

The preliminary results of the survey helped lead to the decision to provide not a single 450-bed hospital but a series of small local units instead. It seemed that this system would have several advantages over the traditional hospitals. It would be helpful to spread out the most dependent and disruptive residents among the more able, who would also be able to contribute to their care. There would be advantages in bridging the gap between home and institutional care; parents from any given area would know what unit served their particular area and the living unit staff might get to know the families while the clients were still at home. The proposed system would also bridge the gap between hospital and local health services and the general practitioner—a gap which has always led to inefficiency under the old administration of the National Health Service and which the administrative reforms of 1974 are intended to help correct. Finally, people with responsibility for local social services and parents' societies might be able to take the sort of special interest in one or two living units which would help maintain pressure for higher standards as well as possibly bringing community contact and help.

Stages Four and Five—The Results

The New Units—Four new units for children have been designed to cater for total population of 100,000 people, from which, as the survey showed, only 20 or so children were receiving residential care. These hostels then were designed to offer a place to every child in that population for whom residential care was required. It was predicted from Table 1 that of these, five would be unable to walk, six would have severe behavior disorders (two of these would also be incontinent), three would have no behavior disorders but would be incontinent, while the remaining children would be continent, ambulant and have no severe behavior disorders. The fifth children's unit in Dorchester serves a total population of 200,000. Only 'hospital' category (non-ambulant and severe behavior-disordered) children are eligible for admission. The predicitons, on the basis of the survey findings, have been found to be sufficiently accurate to inform planners implementing policies.

The one hostel for adults opened so far has provided a home for the 25 most profoundly handicapped and behavior-disordered adults from a total population of 50,000—all of whom were in institutional care already and all of whom are the sort of people that *Better Services for the Mentally Handicapped* says will be the future responsibility of the health service.

The basic criterion is that the locally-based new units will be "feasible" if they can meet the residents' needs at least as "well" as, if not "better" than, existing hospital units which are centralized and staffed continuously by specialist medical and nursing personnel.

The hostels have been designed from the start to be "domestic in character." Although, with 20 places, they are clearly much larger than an "ordinary" home, they are also much smaller than the traditional ward which often has 40 beds or even more. Other "domestic characteristics" have been the furnishings and fittings. The first unit is a converted large house in a residential area of Southampton. The other units have been purpose-built. The sites used include psychiatric hospital, district general hospital, and a vacated annex of a general hospital. However, all of these are in the center of towns, are autonomously staffed, and open onto local residential neighborhoods.

The hostels provide a far more "domestic" setting than any hospital ward. Residents have their own bedrooms, or they share with up to 5 other people rather than in dormitories of up to 20 or 30 people. They have separate dining room, lounge, and play area, as opposed to the traditional large single hospital "dayroom." Food is prepared on the spot rather than delivered and served up from trolleys. There are ordinary bathrooms instead of "ablution blocks." Furnishings and fittings are the kind found in homes, not hospitals. They also have their own fenced garden which opens onto the road as does that of any other house in the area; they are sited within easy walking distance of the local shops and recreation facilities, and they are easily accessible with convenient public transport.

The Staff

The minimum ratio of staff to residents is one to five at any time of the day—which was roughly in keeping with Home Office standards for children's homes when the first units were set up. Some staff live in the units—in separate apartments or "bed-sitters." They are recruited especially to work in the hostel and cannot be transferred to another unit as the need arises, as often happens in hospital settings. When the first unit opened, the idea was that staff should not be recruited solely from among the specialist nurses for the mentally handicapped, but should have experience and/or training in residential child care. In addition, a short orientation course, designed with the help of the research team and administered by the Hospital Management Committee, was provided for all staff recruited before the units opened. Staff in the units now include specialist nurses—often at the head of the unit—as well as people who have received other forms of training. None of them, however, wear uniforms and they take their meals together with the residents. In traditional units the staff are recruited by the managers and allocated as desired to the individual wards. Staff wear uniforms and take their meals separately from the residents in canteens for which there are separate food purchasing and catering arrangements.

Administration

This is a feasibility experiment. When it began, it was suggested that it would not be possible to cater to the demands for residential care for *all* of the most profoundly handicapped and disruptive clients outside of traditional large hospitals staffed continuously by psychiatric and nursing staff who had specialized in the care of the mentally retarded.

The criteria of administrative feasibility, therefore, included that it should be possible to: set up locally based units, i.e. to design them, to find local sites or buildings for them, to get planning permission for them, and to build them at a reasonable cost per place. It would also be necessary to recruit staff at reasonable salary levels up to the agreed establishments and to train them. It would also be necessary to identify all geographically eligible clients whether in hospital or at home, secure permission from their parents to transfer them from existing units to the new local facilities.[15]

These criteria apply to the setting up of the units. Others apply to their maintenance. If feasible, the children identified as eligible were to have the characteristics predicted from Table 3. The staff were to be able to "cope" with all referrals without excluding people as "unacceptable" or as "in need of hospital care" and without having to place children on the "waiting list".

TABLE 3.—*Severely retarded, 15–19 years, Wessex and all Wiltshire. Incapacity by diagnosis*

Diagnosis	NA	Incapacity (percent)			Total known equals 100 pct	Total
		All SB	SI	CAN		
NK and others	5.9	11.8	....	82.3	17	17
Down's syndrome	2.5	6.1	0.6	90.8	163	167
Clinical conditions (not Down's syndrome), very often associated with mental handicap, e.g. microcephalus	28.1	9.4	9.4	53.1	32	32
Cerebral palsy	37.7	6.6	9.8	45.9	61	61
Major congenital abnormalities	8.1	16.2	8.1	67.6	37	37
Epilepsy	2.7	32.9	15.1	49.3	73	74
No clinical sign of brain damage	2.3	14.6	5.2	77.9	213	220
All diagnoses	7.9	13.4	5.9	72.8	596	608

Table 3 illustrates the range of mutually exclusive clinical conditions found among a complete cohort of severely retarded adolescents and relates these to their behavioural repertoires. Between a quarter and a third have Down's syndrome, (D). A third have, respectively, conditions very often associated with mental retardation (MD)—these include rare biochemical disorders like phenylketonuria, galactosaemia, lipoidoses as well as obvious abnormalities of head size like micro-cephaly or hydrocephaly; cerebral palsy (C.P.); major congenital abnormalities (MA); and epileptic convulsions (EP). The remainder, just over a third, have no clinical signs of brain damage (NBD).

This table also shows that, although much needs to be done in improving their environments to develop their behavioural repertoires, by adolescence nearly three quarters are continent, ambulant and have no severe behaviour disorders. It also highlights the fact that, with various exceptions, clinical conditions have little specific effect on the individual's behavioural repertoire. The exceptions are MD and CP where cerebral palsy is likely to decrease the possibility that the individual will walk without help, and epilepsy (EP) where there appears to be an increased likelihood of disruptive behaviour.

They were also to carry out their duties of treating any illnesses (including convulsions) as they arose or by referring the clients to the appropriate specialist in the general hospital for highly technical treatments, keeping accidents at least to the levels obtaining in traditional units. While they were to detect and deal with or prevent staff neglect or punishment of clients, they were also required to avoid routine care practices observed in most traditional facilities. These included routine practices categorized by King, Raynes and Tizard [16] as "Block Treatment," "Rigidity of Routine," "Depersonalization" and "Social Distance". All of these and other criteria were to be met while keeping running costs within a reasonable level, i.e. comparable with traditional costs.

The front-line medical care in new units was to be provided by a specially appointed general practitioner doing three sessions per week, and all clients accepted by the staff of day facilities were to attend these—the children, local special schools; the adults, local adult training centers; and the local authority, social service departments were to provide social work to clients of new units as to all local citizens. However, the residents were to remain the clinical responsibility of the consultant psychiatrist from the traditional hospital and the administrative arrangements for the new units were to be carried out by the people running the traditional hospitals.

Space does not permit a detailed description of the extent to which each of the criteria have been met. Some results have been described;[17,18,19] others are being written up. In all but a few aspects of some, all criteria have been met in the new units. On the other hand, efforts to implement many of these policies by providing additional resources to existing traditional units have so far been much less successful. Only a tiny proportion of the clients admitted to the new units from existing hospitals have had to be transferred back to the hospital because of disruptive behavior. Some details on costs are also provided later.

Some achievements in the new units have also been surprising—thus in the oldest established unit no less than half of the children go home every weekend to stay with their families.

The Hospitals

Whatever features prove advantageous in new locally-based units are likely to be valid in the existing hospitals if indeed they can be implemented there. Wessex has been energetic in attempting to "align" the hospitals so that they serve a defined local catchment area. Residents in hospitals are typically gathered in from a wide area, and Wessex has found that its institutions are no exception to the general rule: when the first new unit was set up, 11 children came from 7 different institutions, 3 of them between 30 and 40 miles—in different directions—from their home. Residents in hospitals have not only traditionally gone where there was a bed; they have, within the hospitals, been divided by degree of ability—"highgrade," "lowgrade," physically disabled and so on.[20] So the task of "sectorizing" all hospital units, moving all hospital residents to units within the hospital which can be quickly identified as "belonging" to a specific area, is a huge one. It is now being attempted in Wessex with the help of the register, but the problems of securing agreement to these policies and the limitations of overcrowding and poor design in existing hospital wards have delayed the implementation of this policy. Efforts have also been made to enable the hospital personnel to share the assumed advantages of "domestic" settings. Wards are being converted in attempts to give residents privacy and some semblance of "normal" living. The operational policy drawn up for the new units has also been adopted for the hospitals and has been the basis of the way they are run since 1969. However, despite additional budgets for staff increases, it has not been possible in existing hospitals to recruit up to the levels in existence before the new increases were agreed. In addition, remodelling the existing wards is proving very expensive and it involves inconvenience and discomfort to both staff and residents.

Measures of Change Between Control and Experimental Units

We are now collecting and evaluating comparative data on changes which have occured over time among the clients and their relatives. There is a "control" group of children and families which is assessed and compared with those using each new unit. As the children's units were the first to be established, the results so far are confined to the experience of the first children's unit. This has been in operation for over four years: it caters for all the children in need of residential care whose family lives in the eastern half of Southampton. The equivalent children from the western half of the town receive residential care in traditional hospital settings.

The Children

On the very general criterion that the new units would be "feasible" if they meet the children's needs as well as, or better than," existing units, the first hostels can be said to be "working."

A comparison of the progress of children in the first experimental and control areas[21] showed that as measured by changes in group mean raw scores on the child development schedule, experimental children made more progress in the areas of eating skills, table manners, mobility, washing, dressing, toileting, speech, appropriate general behavior and appropriate emotional response. In three areas—eating skills, dressing, and appropriate general behavior—the differences in progress were statistically significant. The areas in which the control group made more progress than the experimental group were inappropriate general behavior, inappropriate emotional response, habits (e.g. thumbsucking, rocking, etc.) and sleep.* The experimental group showed gains in all behavioral areas except 'inappropriate' general behavior where the mean raw score for the group was the same after a four-year interval. In 3 out of the 11 behavioral areas which measure 'appropriate' behaviors, the mean scores of the control group decreased over the four-year period (i.e. in mobility, speech, and 'appropriate' general behavior). Among the experimental group of children, those who showed most gains in behavior when compared to children with equivalent handicaps in the control group, were those with the most severe physical handicaps—that is, children who remained nonambulant throughout the four years of the study.

A preliminary report of the team pointed out: "If this unexpected finding is replicated in the future results from other experimental and control groups, it will seriously challenge the widely held view that for this category of child in particular, hospital care under the aegis of trained nurses is not only the treatment of choice, but that lack of such treatment in situations outside of such hospital settings could seriously decrease the child's life chance."[22] However, changes in average scores obtained in this way are likely to be insensitive to the effects of environmental differences of this sort. Alternative methods are being developed to assess these.

The Parents

The new units "work" for the families with handicapped children in that there is no waiting list for places, even though these units are the only ones available to serve their catchment areas. It has been found that parents of children in the first new unit for which results have been analyzed have a more favorable impression of the care their children are receiving than the parents of children in the traditional units. They have had the chance to talk more to the staff of the new units, to visit more before, during, and after their child's admission, to see and to participate in more activities of their children on the unit and to take their children home on visits. Staff had more often visited them at home before the child went into the hostel and consulted the parents in planning the admission.[23]

The Staff

The new units "work" for the staff in that in only one of them has there been difficulty for a short period in bringing staff numbers up to authorized levels and there has been no problem in replacing staff who have resigned. Most members of staff are recruited from the local town. In the traditional units, there is still great difficulty in recruiting staff to the level funded; most of the staff are recruited from outside the area. This suggests that local people are more likely to be attracted to work in the new units than in ill-designed, overcrowded traditional wards a long way from the residents' homes and from their own homes.[24]

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*Appropriate general behavior includes such behaviors as a child's appreciation of danger, the appreciation of his own possessions, looking at pictures (illustrations in books), etc.

Inappropriate general behavior includes such behaviors as being very noisy, destroying furniture and/or fittings, etc.

Appropriate emotional response includes showing response to music, enjoying special outings, showing affection, etc.

Inappropriate emotional response includes not crying when hurt, having periods of withdrawal for no clear reason and never laughing.

Factors Influencing the Quality of Residential Care

We were able at the early stage to explore the factors which make it difficult to avoid a management pattern which includes block-treatment rigidity of regime, depersonalization and social distance. This is not a question of the formal qualification of staff: some of the new residential units have nurses in charge of them who have had the same training as those working in traditional wards. One conclusion at the moment points to the major limitation set by staffing numbers—not overall, but of their deployment at given times during the day.[25] Given existing staffing ratios at any time of the day in traditional hospitals, it is virtually impossible to avoid these negative features of child management. The management practices appear to influence the progress of the residents through the way in which the staff contact or ignore certain classes of resident behavior throughout their waking day.

The measures of block-treatment, rigidity, social distance and depersonalization were helpful indices of quality of care in guiding the development of the new units. However, they have proved too crude and insensitive as measures for monitoring:

- Changes in "quality of care" within the same unit over time.
- Differences in "quality of care" between units at the same time.

Measures which are objective, reliable, and which relate to the progress made by the children being cared for are urgently needed. Answers are required to such questions as: To what extent is the quality of care related to:

Staffing ratios on the unit at any time?

The training received by the staff?

The monitoring and guidance given by the supervisory staff?

The materials available to the children?

The degree of participation of parents and others from outside of the unit?

The degree of participation of social workers, health visitors, and other professionals from outside the unit?

"Quality" measures (dependent variables) need to be sensitive to changes in these independent variables if their relationship is to be assessed. The team is developing measures which assess the extent to which staff are arranging the clients' environment so that clients might develop or maintain their range of skills and abilities.

The validity of these measures requires testing in short and long-term studies to see whether high scores are associated with "progress" and low scores with "failure to progress" of the residents concerned. In addition, more work is required to test whether changes in staffing-ratios, etc., are associated with changes in these scores.[26,27]

Similar measures are required for assessing, over long periods, the quality of care provided for retarded people living in their own homes, and the extent to which this is determined by the management practices of the other members of the family and the guidance given to them by the health, education, and social work professionals from the agencies involved. Of particular importance is the development of methods by which agency personnel intervene in "crises" which arise in residential and domiciliary settings and which often result in the "buck-passing" of the retarded person from one setting to another, e.g. from home to residential care, or from one residential setting to another. The team is now developing such measures as well as systematic ways of joint-goal setting, attaining and monitoring by teams of agency personnel, family members, and the retarded person.[28]

Exclusions from the New Units

Initially, only 3 out of a total of 90 children from a total population of 600,000 were found to be unsuitable for the units. One was transferred back to a traditional hospital because his behavior presented a problem. He bit other children when in the new unit; he still bites people now that he's back in the traditional unit. The second was thought to be a problem because of his "size." One child was refused admission because she suffered from status epilepiticus, and it was thought that a houseparent without nursing qualifications could not legally give her an anticonvulsant injection. More recently, three more children have been transferred back to the traditional hospitals because of behavior difficulties—two from one unit and one from another. In the latter case, the decision to transfer was associated as much with staff-parent conflicts on management as with the child's behavior.

The one adult hostel has been able to receive all the most profoundly retarded and severely disruptive adults from its institutionalized population. One of the adults has been transferred back to the traditional institution because of behavior problems in the new unit—his behavior problems persist in the traditional hospital.

Our observations so far suggest that disruptive behavior has not been altered in the traditional units. It continues but is dealt with by practices regarded as unacceptable in locally based units. These include the use of living environments from which all civilized furnishings and fittings have been removed, putting children on wards with adults who retaliate if bitten or pushed, the use of very large doses of tranquilizers, mechanical restraint or seclusion in locked rooms.

This work has also provided clues for approaching the humane management of clients with severely disruptive behavior. These people are excluded from environments which they disrupt. As mentioned, a small minority of clients in the new Wessex units have been excluded and transferred to traditional hospital units.

There are now effective and humane methods for weakening very disruptive behaviors which have been acquired over long periods by the differential attention they attract from staff and relatives alike. The most important of these is staff or relative counselling to ensure that others only contact him or her during periods of engagement with materials and not during periods of disruption. If the environment cannot support the provision of materials or the differential contact from others, these features must first be attended to. Procedures of "time out" and "overcorrection" can also be used.[29]

If all of these fail, then and only then is it necessary to consider the use of punishment procedures to weaken these behaviors if they endanger the individual, his peers, or the staff caring for him.

The ethical problems involved in these procedures also make it essential that the goals set and implemented are carefully discussed and agreed with the client or, where this is not possible, with relatives or an advocate.

The proximity of relatives to any facility where such procedures are to be used, therefore, becomes essential if the relatives are to participate in the program.

Given the development of aids whereby parents and caring staff can learn to provide engaging environments, it is likely that the proportion of clients with very disruptive behaviors, already very low now, will decrease still further.

These techniques now give credence to the general aims people have so long espoused—"normalization," "individualization," and "continuity of care." The ability of people working from large institutions to deliver these environments and the techniques which go with them must be carefully investigated, as must our techniques for monitoring the extent to which they are able or enabled to do so.

The Cost

This is important for making comparisons between the running costs of the new units and those of traditional wards. There is no evidence at the moment to suggest that *if* staffing ratios in the hospital wards could be brought up to those of the hostels, there would be significant differences in the running costs of the two types of establishment. The research team has in fact worked out that if the three large hospitals had spent the same per patient on staffing as the hostels in the year 1971-72, the revenue costs to the N.H.S. of the two sorts of care would have been the same.[30] The revenue cost per resident per week in the Wessex experimental units is now lower than that for ALL residents (children and adults) in a newly built traditional hospital in central Southern England.

Land and Other Costs

The revenue costs to the N.H.S. are not the only relevant cost in the comparison of hospitals and locally based units. Differences in costs to patients, parents, and families are also important, but have not received research attention. It appears likely that local units would at least reduce the travelling costs of these people. Another major cost is capital cost, including the cost of land. A study of land usage revealed that in

Wessex there is over four times as much land per patient in the large hospital as in the locally based units. Much of the large hospital land which originally may have been well outside towns is now, with the spread of urban development, in prime residential areas and valued at around 20,000 pounds per acre or more. It has been estimated, making certain assumptions about land values, land per patient, etc., that if all residents of some traditional hospitals were transferred to locally based units and the existing hospital sites sold, then there could be a capital saving.

Much of the land of existing mental handicap hospitals is being declared "surplus" and sold. If these sales proceeds were to be ploughed back into providing better facilities for mentally handicapped people, they could make a significant contribution to improving the service in accordance with White Paper policy.

The experiment indicates that a completely locally based pattern of residential care need not be more expensive to run than a service of similar quality provided in traditional large institutions. It has been estimated that if all mentally handicapped people in this area of Britain alone were tc be provided with staffing ratios similar to those in the existing hostels, then the hospital authority would have to be prepared to pay between 750,000 and 1 million pounds more a year in running costs on those people defined as its responsibility. It is doubtful whether it would be feasible to run locally based units with the same staffing ratios as in the hospitals. So, if all these people were to be transferred from large hospitals to locally based units, it is unlikely that an increase in expenditure of this kind could be avoided. If people remain in hospitals with lower staffing, current levels of expenditure could be continued. It is perhaps a measure of the general neglect of this group of people that 1 million pounds additional expenditure would mean, in Wessex, an increase of 40 percent on the present hospital revenue allocation to mentally handicapped people.[31]

Conclusions

On the results so far, the Wessex experiment shows that hospital authorities in Britain can make a far more adventurous contribution to changing the pattern of residential care for the mentally handicapped than they have done in the past. It indicates that a completely locally-based pattern of care will be possible within the terms of the central policy laid down in *Better Services for the Mentally Handicapped* and within the legal divisions of responsibility between health and local social service authorities, if only these authorities seize their chance to plan for radical change.

The Wessex experiment indicates that even the most severely multiply-handicapped child can be cared for in a domestic setting near his own home, at least as well as in an existing traditional institutional ward—that indeed these children are the very ones who seem to make the best progress under such a regime. It indicates that there is no evidence why even the most profoundly handicapped and severely disturbed adults cannot also live in locally-based small units.

The continuation of residential care in the community, however, has yet to be observed. Until a follow-through can be made of those locally based children who move to an adult hostel in the same neighborhood, the advantages can only be assumed. It seems unlikely that progress made by children in the locally based units will be maintained or continued when as adults they return to traditionally designed and staffed adult wards of the hospital, or possibly move to an adult hostel where no links have been established prior to transfer to bridge the child/adult move.

Until hostels for children and adults from the same area have been established there is no way of measuring any gain or loss in the rate of progress. In Wessex this continuity is not yet possible, but we hope that the translation of plans into buildings will allow such an evaluation to be made in the future.

To what policy implications do the preliminary Wessex result point? It may be asked, "Do the gains in terms of parental satisfaction, the quality of care received by the clients, and the modest comparative gains in progress of the clients, warrant changes in policy involving the setting up of any further residential services for the retarded in locally-based domestic settings rather than in large hospitals? Do not the problems of providing adequate care in existing large hospitals arise from simple lack of resources which could be made good without abandoning the facilities and the policies for remodelling and expanding them?"

These questions suggest a wide range of possible research projects to evaluate the effectiveness of a range of strategies aimed at avoiding some of the worst features of neglect now apparent in existing large hospitals, and the scandals that appear to occur in them with a degree of regularity.[32,33,34] However, the Wessex results suggest the urgent need that people promoting the option of well resourced large institutions, run and staffed by specialists in mental handicap, should spell out systematically the goals which they aim to attain in environments which are necessarily far from the homes of the clients and from the other facilities available to all citizens. These objectives have not so far been documented, despite thd fact that proponents of this option assert that their objectives can only be met if such facilities are equipped with a wide range of expensive technological laboratory facilities.[35]

To be sure, the lot of residents in existing large facilities could be improved in many ways. The provision of general practitioner medical care with adequate referral to general hospitals could result in the identification and treatment of organic conditions not now so treated. It is, however, most unlikely that the provision of medical specialists who could undertake complex neurological and biochemical investigations would make a significant contribution. In a recent Finnish study, 338 severely retarded people were subjected to the most intensive biochemical, cytogenetic, electroencephalographic and neuroradiological investigations. Only one subject was found to be suffering from an organically treatable condition and "improved" on the removal of a cerebral tumor.[36]

On the other hand, in the last 10 years impressive advances have been made in techniques for strengthening skills in selfhelp, social interaction, play and cognitive activities of children and adults, regardless of the range of their behavioral repertoires or the organic limitations to them.[37] These developments highlight the importance of the physical and social environment of the individual as a key determinant of the skills (adaptive or maladaptive) which he will acquire. Moreover, they give clear guidelines, backed by laboratory experiments, on how to identify the features of the environment which are responsible for maintaining components of the behavioral repertoire, and for changing them in ways that enlarge or diminish the repertoire.

These developments point to the key part played in the individual's environment by those who contact him most frequently in the everyday situation. They also indicate that individuals have dignity and self-esteem to the extent that they are able to control their immediate social and physical environments in ways that are acceptable to other people in those environments. When mentally retarded people require the help of social agencies, it is because they cannot control their immediate environments in a way that is acceptable to others—to their parents, their siblings, their peers, their teachers or their employers. Indeed, the most difficult problems arise when they learn to control their parents and peers by their disruptive behavior.

It would appear that the future interest of retarded people lies in their developing a wide range of socially acceptable and creative skills, and that if they are to do so, their parents, relatives, and peers are in the best position to help them.

The provision of decentralized, locally-based units appears to allow the mentally retarded person to maintain contact with those who are his strongest advocates. Any strategy which places obstacles between him and these advocates requires the most careful scrutiny. When professionals take on the role of advocates, it is likely that their most powerful allies for ensuring that they are given richly stimulating environments in which to work are also the clients' advocates.

Dangers of Possible Reversal of Policy

This work has also provided clues for approaching the humane management of clients with severely disruptive behavior. These people are excluded from environments which they disrupt. As mentioned, a small minority of clients in the new Wessex units have been excluded and transferred to traditional hospital units.

Our concern is that the frequency of such exclusions and transfers from locally-based units to traditional hospitals will increase in the future unless specific steps are taken to prevent this from occurring. The consequences of continued policy of "exclude and transfer" are:

- A build-up in the place to which the people are transferred of a collection of people with severely disruptive behavior.

- The daily living environment of the setting to which the person is transferred is likely to be denuded of many of the furnishings and fittings and of the wide range of objects which are part of a "normal" living environment. This, together with the concentration of disruptive people, is likely to make it an environment which is unattractive to direct-care staff, to volunteers, to supervisors and monitors of the facility, as well as to planners and providers of such facilities.

- Such an environment is also likely to strengthen and maintain the very disruptive behaviors it is intended to "treat"; the clients there do not have the materials with which to engage adaptively throughout the day. Nor are there staff, parents, or volunteers available to contact and interact with clients when they engage in socially acceptable conduct and, in this way, strengthen acceptable conduct. Staff in these settings must resort to the use of mechanical or chemical restraint of clients, and scandals may arise when these techniques are aired in the mass media.

- These clients are unlikely ever to be able to return to their home or neighborhood because they never have the opportunity to acquire acceptable skills and abilities which generalize to the home environment or the richer and more complex environment of the locally-based unit.

- This sequence of practices is sometimes justified *a posteriori* by a series of arguments which, however, mystify rather than clarify the phenomenon. Thus it is said that:

The disruptive or profoundly handicapped clients do not "appreciate" a rich environment near to their own homes; the more able and acceptably-behaved clients do.

The disruptive clients often tend to have "difficult" or "disturbed" relatives whose management practices with their children strengthen the client's disruptive behavior. Evidence is offered of the parental "disturbance"; this may include their assertive advocacy on behalf of the clients and its direct or inferred criticism of staff practices towards the clients. It is therefore suggested that contact between the parents and the client is "non-therapeutic" and that transfer of the client to a distant unit is not only expedient but therapeutic. At the same time, it is argued that the locally-based unit is more appropriately used by clients whose parents are not assertive, not critical of staff practices, and therefore likely to benefit from use of the facility.

The disruptive client is said to need "intensive therapy" in the "special unit" to which he or she is transferred. It is accepted that the environment to which the transfer takes place does not provide "intensive therapy" at the time of transfer. It is also accepted that there are, at present, no documented models of such units for profoundly handicapped disruptive clients. The transfer is accompanied by an assertion that such a unit should and will be provided at some time in the future.

The presence of disruptive clients who are excluded from "normal" environments is said to make essential the provision of isolated hospitals and personnel with the specialist skills of "containing" degrees of disruption which "untrained" people cannot tolerate or are said only to exacerbate.

The existence of locally-based residential units, accessible and therefore open to continuous public and parental scrutiny, well-staffed and provided with materials present in "normal domestic environments," and which include profoundly handicapped and disruptive clients, presents data which challenge these arguments. Nevertheless, the arguments continue to be advanced in support of traditional practices. They may also set the occasion for eroding the advances that have been made in the provision of accessible, open rich environments for profoundly handicapped or disruptive residents.

Can the Reversal of These Policies be Prevented?

The practices of "transferring" clients from one setting to another when disruptive behaviors occur (either of the client of the parent) or of transferring staff from one unit to another when "personality difficulties" occur has often been claimed as the main advantage of the traditional large institution. Our observations suggest that "transferring" is one of the main factors perpetuating the disruptive behaviors, weakening the acquisition of socially acceptable repertoires, and maintaining the mystifying "explanation" of the origin of disruptive conduct.

These practices are, however, likely to continue because at present the staff concerned have no other responses for solving the problems of engaging profoundly handicapped or disruptive residents in locally-based facilities.

An important recent advance has been the documentation of practice guidelines informed by research evidence. These are now available for implementation by agency personnel at all levels.[38]

The first requirement is that staff, parents, and volunteers in these situations must learn to contact clients frequently, consistently, and systematically when they are engaged in socially acceptable conduct. Similarly, they must learn to systematically and consistently ignore the clients when their behavior is socially disruptive. Where it is necessary to intervene during periods of socially disruptive conduct, socially acceptable practices which are both humane and educational must be learned to weaken this form of conduct.

These practices are, of course, used in most everyday social interaction. The task is merely to ensure that terms are carried out systematically and consistently by all people contacting the clients concerned. It is now possible both to monitor the consistency with which staff, parents, or volunteers observe these guidelines, to counsel them on where they are failing to do so, and to assess the effectiveness of such counsel by the extent to which the practices approach the standards required.

It is also possible to sequence activities within residential and day settings so that residents do not spend long periods "waiting" for opportunities to engage in socially acceptable activities; disruptive conduct is most likely to occur during these periods of "waiting" or "disengagement."[39]

It is also possible to identify materials and activities which are of particular interest to individual residents who have unusual interests and to make these available at all periods of the waking day.[40] The richer the environment, the better staffed it is, and the greater the participation of parents and relatives in the program, the more likely it is that the program will be implemented consistently in all settings.

The proximity of relatives to any facility where such procedures are to be used, therefore, becomes essential if the relatives are to participate in the program.

Given the development of aids whereby parents and caring staff can learn to provide engaging environments, it is likely that the proportion of clients with very disruptive behaviors, already very low now, will decrease still further.

These techniques make credible the aims people have so long espoused—"normalization," "individualization," and "continuity of care." Profoundly handicapped and disruptive retarded people need no longer be excluded from these aims.

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Biography

ALBERT KUSHLICK completed his undergraduate medical training in South Africa. After working in a hospital for mentally retarded persons in England, he lectured in social and preventive medicine at Manchester University. He undertook studies on the epidemiology of mental retardation while working as a medical officer in a community mental health department.

He is now an external scientist of Medical Research Council and directs a Health Care Evaluation Research Team in the Wessex Region of England. The team is concerned with the development of alternative forms of comprehensive health and social service care for mentally retarded people and for the very old.

20. ComServ, Canada

G. Allan Roeher

The increasing concern to provide an adequate range of local community services for individuals with developmental disabilities has been expressed in growing interest from various levels of government and from non-governmental organizations in developing services which are comprehensive, systematized and regional.

The challenge today is to realize rational, effective, and cost-beneficial human services delivery systems. We need to provide a wide range of options within these systems and this, in turn, depends on unified planning, coordination, continuity, and harmonious implementation. The cost of such an approach will need to be economically realistic. The systems also need appropriate legislative authority or power to redirect current and future efforts to adapt to changing needs.

ComServ is an effort to find such a system and, through evaluation and development projects, to make it nationally applicable. It is a cooperative effort between the Canadian Association for the Mentally Retarded and the National Institute on Mental Retardation which it sponsors.[1]

Failings in Present Approaches to Service Delivery

There is a public misconception that only handicapped persons require a local range of human services. But the average person, throughout his or her lifetime, requires many years of education, training, medical care, counselling, and other types of help provided at public expense before achieving independence. Even as self-supporting adults, everyone is likely to need medical attention, aid in times of emergency, income maintenance, counselling, social and recreational outlets, religious fulfillment, etc. in order to enjoy a normal life. Retarded persons have the same needs for support and assistance but sometimes more so. The challenge is to meet all the needs of a group of persons who, because of their handicaps, are more limited than others in their ability to meet the contingencies of life. But the shift of expectations from "custodial care" to "contributing citizen" creates service problems which remain largely unsolved.

Current community-based services may meet the needs of some but not all retarded persons. Much local provision has been based on crisis situations and immediate needs rather than on long-range overall planning. Consequently, the typical service response in a crisis situation is still to take the retarded person over completely by admitting him or her to total institutional care. Alternatives to the institution are few, and existing community service resources are limited. The present uncoordinated multiagency approach to service delivery also tends to create a pattern of fragmented, duplicated, and discontinuous services. These failings are characteristic of a "non-system."

The problems of discontinuity and fragmentation become particularly acute when a person requires services provided by a number of unrelated agencies. For example, a person returning to the community from an institution may require vocational training for a period of time, money to live on, then assistance in obtaining a job and ongoing support in order to keep it. This individual may also require a residence which provides individual supervision, special transportation arrangements in order to reach training programs and work, and may, at the same time, be receiving one or more special therapies related to some physical or other problem. The typical "non-system" can rarely cope with such complex coordination problems.

A major study by the Commission on Emotional and Learning Disorders in Children (CELDIC)[2] pointed to organizational barriers as a major deterrent to effective mobilization of resources. Members of the Commission and others have postulated that adequate human and other resources may be available to meet the needs of children with emotional and learning disabilities (including the retarded) but that these resources are deployed in such an inefficient and fragmented way that there is, at least in part, an illusion of an acute shortage.

There are no easy solutions. Efforts to coordinate agency services have seldom overcome the problem, nor has consolidation of small agencies into super-organizations, whether public or private. The vacuum created by failures of existing agencies is filled by new citizen-action groups which compete with them. The new "grass roots" movements, in turn, tend to lose their flexibility, innovative problem-solving approaches, and citizen-action orientation to become extremely rigid, administration-bound, and decreasingly involved. These phenomena affect public and private agencies alike.

This, then, is the position. There is a need to improve both the quality and quantity of services at a local level. The present local services do not generally meet all individual client needs elsewhere. Services are by no means continuous or comprehensive. Services in an area need to be linked together in some way without reducing local control and the sensitivity of such services to local needs.

In increasing the number of services provided directly at the local level, state or provincial government departments not only continue to extend central power into local areas but also risk stigmatizing persons served because these services are "government" ones. Central government departments have not yet established a mechanism through which to coordinate either their own services or the new services of local agencies.

Many services also unnecessarily segregate a minority group from the social mainstream, with the result that many people fail to become as self-sufficient as they could be. Because of the human tendency to adapt to the situation as it is, no matter how limited, patterns once established tend to continue. Those in the minority adapt to their inferior or deprived status and the rest of society seldom sees that things could or should be any different. This situation tends to perpetuate itself generation after generation as children learn to model their beliefs, aspirations, and behavior after those of their peers and parents. Both the majority and the minority are thus rarely awakened to the fact that it is possible for the minority to participate more fully in the community and to share the rights and responsibilities of the majority.

Finally, there is the problem of agencies becoming ineffective or irrelevant. Having fulfilled the mission for which they came into existence, they fail to adapt or redirect their efforts to changing needs; they fail either to die or to satisfy essential needs.

These various factors of service fragmentation, duplication, lack of coordination, and maladaptation contribute both to the spiralling cost of services and to nonrealization of potential.

Basic Characteristics of ComServ Approach

We now have considerable information about the essential characteristics of an adaptive and effective (comprehensive) community service system which serves contemporary needs. Developments in the rehabilitation field, for instance, have, over several decades, indicated that it is less cost-beneficial to use large-scale, all-inclusive facilities than existing single-purpose or more flexible agencies. Health, education, and social service planners have come to appreciate that inflexible single-path structures must be replaced with those which allow for arrival at the same end by a variety of means. The most effective system for one area is not necessarily the most effective for another where size, social patterns, economic situation, and population structures may be very different. Any planning which unnecessarily restricts options is apt to let the approach define the service or to limit the effective ways in which services might be delivered: the means may become the end instead of the end remaining the foremost concern. As an alternative, modern decision and systems theory would appear to dictate that multiple paths should be available to attain the goal, and that as many implemental options as possible be defined and accessible.

Regional Planning

A regional approach to the delivery of services is fundamental.* Regionalized service systems offer advantages over local service systems in that they promote comprehensiveness and coordinated planning of services, permit greater specialization of services, counter excessive parochialism, provide greater cost efficiency through economies of scale, better utilization of expertise, and have greater impact on other agencies and governments.

Regionalized service systems also offer advantages over centralized (provincial/state) services in that they permit closer client-family ties, have a greater sensitivity to local conditions and needs, make for increased citizen identification with services, lessen communication problems, encourage greater innovativeness, are more cost-efficient, and reduce political distortion.

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*Regional means areas within provinces (or states) concerned with delivery of health, education, and welfare services. The terms local and community, as used here are synonomous (local is where the person is).

Yet, unless there is a large enough population base to justify establishing services and facilities in the region for even the most profoundly retarded, multiply involved children, there will not be true comprehensiveness. In a population base of, say, 200,000, we can expect to find approximately 300 severely and profoundly retarded persons of whom about 60 (mostly children) will be profoundly retarded. If a region has many fewer than 50 to 60 profoundly retarded persons, it may not be possible to justify the necessary high-cost specialized services within the region, and these persons will have to be sent out of their own regions, which comprehensive community planning attempts to avoid. We still need much experiment before we have final answers, but it appears that for preliminary planning purposes we need a population of a least 200,000 persons in a completely comprehensive ComServ region. Deviations from this figure should be specifically justified and the dangers inherent in low or high-population regions carefully safeguarded against. Certain rural regional areas may not, for these reasons, be viable settings.

Regions serving a specific group, such as mentally retarded people, should be planned to coincide with, and take advantage of, existing geo-demographic service patterns and be defined and subdivided by boundaries which are co-terminous with those of established health, education, and welfare areas. It may be desirable to subregionalize services within a large regional system, instead of attempting to coordinate specialized services between regions which are borderline in meeting minimum population and other criteria and could be beset with serious problems of discontinuity and low return for efforts and resources expended.

Comprehensive Services and Continuity

An individual must have a range of options within a particular category of service. The major typical components serving the mentally retarded would include:

- Child Development—early stimulation, preschool and school age education; good nutrition; sensory-motor development; social and physical recreational training; and therapy services to the home, care centers, and classrooms.
- Vocational and Adult Services—training, placement, sheltered employment, and follow up.
- Residential Services—foster, adoptive, boarding homes, group homes, apartment living, special small group and respite units.
- Family Support Services and Central Administration—fiscal services, staff development, research and development, public relations and education, transportation, prevention, assessment, family guidance and support, counselling, recreation, citizen advocacy, and income maintenance.

Each of these four groupings can be organized and operated as a subsystem in large regions. In others, perhaps smaller regions, all may be administered within suborganizational structures. Since resources will always be limited, priorities must always be set to ensure equitable distribution of services to the population at risk.

Principles of Organization

Services should be delivered and administered as close to the local community as possible. The advantages of local services include better consumer-orientation, maintenance of family ties, use of existing community resources, and ultimately less expensive service delivery.

Wherever possible, service delivery at the local level should be governed by community boards. These strengthen consumer involvement and orientation, increase community support and understanding of the objectives of the service, and make services more responsive to community needs.

Wherever possible, existing community boards should be encouraged to broaden their responsibility to incorporate the delivery of services for handicapped people. If it is necessary to establish new local or regional boards, these boards should be encouraged to become more generic over time by taking responsibility for some services for nonhandicapped people. These processes contribute to better coordination of services, promote normalization and integration of the handicapped, reduce duplication of services, and provide for effective utilization of existing resources and expertise.

A mechanism to ensure regionalized coordination of service delivery should be developed so that the services from an individual client's point of view are both comprehensive and continuous.

Bodies should be established with consumers or advocates among their members. Such bodies are valuable in monitoring and safeguarding the quality of services and help ensure that services are, in fact, meeting needs.

In addition to sound management principles, services must reflect changing concepts, particularly those of normalization and integration.

Services must also be cost-beneficial and effectively reduce the problem rather than merely ameliorating it.

Change mechanisms must be built into the systems to prevent rigidity.

Subcomponents of a ComServ System

The number and type of services in a comprehensive system will be greater than previously conceptualized, allowing handicapped persons to move much faster towards independence. It is helpful, therefore, for planning and administration to group or organize individual service components into subsystems, according to the type of service provided. All centers providing residential options can be grouped into one subsystem; all the services having to do with vocational training and work form another; services involved with training and education of children comprise a third subdivision; and services providing family and individual support logically form a fourth. The smallest but most important subsystem of the whole is central and administrative services, which helps the entire service system to function effectively. Some means are required for coordinating these "subsystems" into a coherent and efficient "system" of services. The directorate must be staffed by well-trained personnel, experienced in program organization, guidance, and administration. In most regional operations, one or more specialists is needed for each subcomponent area.

It is not possible in this chapter to describe in detail the nature of each type of service to be listed. The purpose is to acquaint the reader with the number and variety of services required in a comprehensive service delivery system and to indicate the continuum of related services in each subsystem.

Family Support Services

The family support subsystem includes a range of services to the family in the child's own home in its task of providing the necessary care—or to the "family" in adoptive, foster, or group home situations. This helps ensure that the handicapped person has the opportunity to live as normal a life as possible. The support services also minimize penalizing the family unnecessarily for assuming the responsibility of caring for their child.

The range of family support services includes: genetic counselling, assessment and diagnosis, counselling, crisis assistance and respite care, visiting homemakers, in-home therapy, parent/child training, recreation, transportation, citizen advocacy, lending library, information resources, financial subsidy, pilot parents, and work with the associations for the mentally retarded.

One of the great challenges to ComServ planning is to ensure that services have sufficient outreach to include all families requiring service, especially in moments of crisis. Some of the listed services may be provided by professional and trained personnel, others by a combination of professional staff and volunteers working together, or primarily by volunteer and volunteer associations.

Child Development Services

The child development service subsystem includes developmental programs for preschool-age children and children with exceptional disabilities and public school education.

Imitation and peer modelling are the most powerful methods for teaching children. Every effort should be made to integrate handicapped children, even at a very early age, with normal children, so they can benefit from the integrated setting.

In addition to extensive staffing, it will be necessary to have a number of special units or programs to provide behavior shaping in special circumstances (hyperactivity, destructiveness, extreme withdrawal, and other behavior problems).

A variety of behavior shaping and behavior management techniques may be used. Multiply-handicapped and severely retarded children may require physiotherapy, speech therapy, and other therapies in order to overcome their physical and other limitations. However, it is important to recognize that even these highly specialized services should be built into community-based child development centers as much as possible.

The range of services include: infant stimulation, child development and training, day care, school preparation, behavior shaping and maintenance of life/developmental (maximization) skills.

Since many of these kinds of activities should begin at home, this subsystem overlaps with family support services.

Although public school education may not necessarily be structurally included within ComServ, the education system has a vital role by offering handicapped children the maximum opportunity for normalization and integration in settings to which society ascribes a high status. School systems have resources often not enjoyed by other service agencies—resources which can be used to reduce the need for alternate special facilities and programs.

The school system's relevant services to handicapped children include: academic skills training, language development, life skills training, socialization, physical education, recreation, vocational preparation, career counselling, cultural enrichment, and remediation for special difficulties (speech and other therapies).

Residential Services

Different residential options need to be provided to form a continuum to promote independence for handicapped children and adults.

The highest priority should always be given to ways and means of keeping retarded persons within their own family homes. This function more logically fits within the family support services continuum, but it is obvious that support services are an important extension of all residential services and form the first line of defense against the need for more expensive residential placements. The next highest priority in residential services includes a range of options: adoptive homes, foster homes (short term and long term), boarding homes, group homes, apartments, nursing homes, skilled nursing care, convalescent hospitals, and other options available in the community.

A number of more specialized residential services are also required to complete the developmental continuum of living arrangements and provide backup to all the other residential options. These include:

- Life support or developmental maximation—to serve children/adults with profound degrees of mental retardation and multiple handicaps where intensive medical and paramedical care is required.
- Infant nursery and developmental programs—for retarded infants and children below school age.
- Child development hostels—for children between three and eighteen who require a typical family type situation with older and younger children.
- Intensive behavior management units—a temporary residence for severely handicapped persons over six years of age.
- Structured correctional group homes—for difficult-to-manage and antisocial persons.
- Training hostels offering:

a short-term service for retarded individuals over sixteen years to prepare for self-sufficient living.

a long-term residence for more severely retarded individuals.

a home for retarded adults who are able to function with minimal supervision.

- Apartments offering:

maximum independence.

co-residence/staff apartment.

a cluster of units.

- Crisis assistance homes—for temporary placement of children and adults where family circumstances make the removal of the handicapped person necessary.
- Habit-shaping unit—a specialized short-term residence for those persons who do not fit into more normal living arrangements and require extensive habit shaping and socialization.

Perhaps in no other area of service is it more important to apply the principle of normalization rigorously. Where a person lives, and with whom, has a great impact on how a person sees himself. It also has a great influence on how others interpret the individual and his handicap. It has been demonstrated that even the most severely retarded and disabled can live in ordinary housing, and seeing this happen creates a powerful, favorable image in the minds of the public.

Adult (Vocational) Services

All adults need adult services, including residential counselling, etc. Not all need vocational services. The latter, however, are of such significance that they are treated as a subsystem. This includes the opportunity to be involved in one or more of: sheltered work, sheltered industry, training on the job, work stations in commerce and industry, trades training and employment, part-time and full-time employment and self-employment.

In addition to providing "places to work" and "meaningful work," the vocational subsystem of services requires a range of activities which support and back up the efforts of both employers and employees.

These services include: selection and assessment, recruitment, prevocational training, vocational exploration and evaluation, work adjustment training, personal adjustment training, skill training, placement, follow up, on-site orientation, job stabilization, retraining.

The vocational service system cannot operate successfully in isolation from other services. This is one of the compelling reasons for having the vocational services system as part of the larger, more comprehensive service system for the mentally retarded or handicapped. The vocational service area must relate to other adult services and operate in conjunction with community-based residential services, the educational system (particularly the secondary vocational training schools), and other support services such as citizen advocacy, recreation, transportation, etc.

Central Support Services

Obviously, a service delivery system, which may include dozens of service units and hundreds of staff scattered over a large geographical region and serving a large population, will require a solid organizational structure and sound administration. The central services subsystem will hold the entire system together and help it to function efficiently and effectively. It includes administration (senior staff), fiscal control, staff development, evaluation, research, and public education.

Governance and Funding of ComServ

The principles of ComServ suggest a need for modification of traditional service delivery mechanisms. Part of the state or provincial government's mandate for service delivery must be delegated to some structure which is closer to the people requiring the service, together with enough power to bring both qualitative and quantitative changes in programs. Mechanisms to safeguard local service autonomy must be considered as well.

In the envisioned scheme, central government retains the comprehensive long-term planning function for the state or province as a whole. It has responsibility for establishing global policies, priorities, and implementive strategies, and for certain general regulations and standards for services which must be set and enforced within all subareas or regions. Central government also needs the mandate and resources to arrange for manpower development and training, obtain appropriate consultation and program support for regional services, provide the major share of operating funds (matching other sources, etc.), arrange for impartial external evaluation of the services it funds, and provide or obtain applied research.

In order to carry out its mandate, the provincial/state government would delegate certain functions to approved regional service systems with appropriate governing bodies (known as directorates). These "directing" bodies may be for special services or for general services. They would be composed of representatives from agencies, voluntary associations, interested professional and public leaders, local and central government, etc. The directorate would have a full-time paid staff and would be given specific powers to carry out its mission effectively.

The functions of the regional service system directing body (or directorate) are: to see that needed services are provided and coordinated in the region, to conduct long-term planning on a regional basis for comprehensive services, to evolve regional implemental strategies, to determine regional policies and set regional priorities, to develop local funding sources and allocate funds, and to employ and direct staff to carry out these functions.

The regional body also needs to be responsible for control and/or direct administration of the services and to have the authority to exercise regulatory powers, to review grant requests, to control the (operating and capital) funds made available from central government, to have the right to purchase services for the client and allocate funds, to contract for provision of services with or without exchange of funds, to control a significant share of governing seats on the directorate, to stimulate voluntary coordination, and to obtain from voluntary and governmental bodies funds beyond those granted from central governments.

Frequently, regional bodies which have no real authority and work only on a voluntary coordination basis (while this may be useful at times) will not be able to develop and manage a full and effective coordinated comprehensive service system.

A regional authority could be quite workable without a legislated mandate of all these powers but would need at least the power of grant review, some control of the granted funds, the ability to purchase and/or contract for provision of services, and to facilitate coordination on a voluntary basis. A regional authority should also have power to administer services directly but this should be used only when economies of scale demand regional rather than local services.

The power to purchase or to contract for services is potentially very important. Even without actual exchange of moneys, a regional authority could have the power to contract with a local agency (for example, a Family Service Bureau for counselling services). The power to allocate funds could meet resistance from both local and central bodies and may not be fundamental to the effective operation of a regional directorate. But some control over "new" moneys involving new services, major expansions to local agencies, and capital projects would help coordinate future developments and avoid overlapping and duplicating of services. Local boards and services might keep responsibility for operating funds for ongoing programs.

Control over a significant number of governing seats on a regional board is a two-pronged proposition, since it covers both the makeup of regional authority and the degree to which the regional authority attempts to influence the makeup of local agencies and boards. In reality, a regional authority probably would not, and perhaps should not, have this second influence if adequate powers are given to the region to allow for coordination.

The final, and most effective power that a regional authority should have is that of fund raising, whether private or public. It must have access to reliable and stable sources of funding which are at least sufficient to provide for its administrative costs as well as for provision of any direct services not already available.

There are several precedents for regional and local authorities having taxing powers, such as school boards and regional health boards. In many instances, municipal taxation is levied for social services. The social service tax and regional health-related tax are a precedent for giving a regional authority both local and regional funding bases.

Voluntary funds and tax levies may form a very small part of the total operating costs and may also have little measurable impact on the central government revenue picture. But to transfer one or both of these sources to a regional authority would provide a most important "psychological" boost to the regional authority by encouraging the coordination of local services and the decentralization of government services. It also provides much needed "flexible" funds.

Since the issue of sources of funding is related to the issue of the composition of a regional governance structure, these issues bear discussion together. When the sources of funds are purely from the voluntary sector, membership on the board is less crucial. A funding base involving some taxation clearly requires that at least some elected officials are members of the board. Between these two alternate funding sources lies a range of alternative funding and governance possibilities.

Client-oriented citizen-action groups who become involved in the direct operation of services may become concerned about their future under a ComServ-type development. There are a number of possible alternatives. It seems best that the directorate be set up as a new independent body, with or without a legislative base on which these agencies should be represented, along with other parties with an interest in services to the mentally handicapped. The agencies might then contract to provide services as part of the regional system governed by the directorate.

For those voluntary organizations who support the notion of the need for ongoing change and updating of voluntary agencies,[3] an alternative would be for the association to get right out of the business of providing services and instead form a new sort of partnership with a ComServ agency.

Program advisory committees would cover services in a subregion—for example, all the developmental centers in a particular part of town. Then, for each service subsystem, there could be a monitoring committee that would relate to the ComServ agency at the subsystem level.

The Implemental Strategy for ComServ

In spite of the present favorable atmosphere, immediate large-scale development of comprehensive services is not feasible for four reasons:

- It would not be possible to reorient all existing services at the same time.

- While much is known about the general character that such comprehensive services ought to embody, more has yet to be learned about the best ways to organize and implement them.

- There simply is not enough money for immediate total implementation, even if the "change force" existed. Although ComServ is geared to use already existing moneys, it will require additional funds and these are unlikely to be generated all at once on the necessary scale.

- Experience has shown that relatively few people fully appreciate the possible complexity of the ComServ system, nor do most realize the extent to which service systems can normalize the lives of most retarded persons.

Before comprehensive service systems advance, a great deal of planning and groundwork will be necessary, including the development of major training and communication programs for both professionals and volunteers in the field. It is expected that the next few years of transition from existing single service approaches to the ComServ system will be turbulent and difficult for staff, volunteers, retarded persons, and their families. It is expected that truly comprehensive service systems will not at first be less costly than "institutional" costs, but since these costs are spread across many different levels of government and funding sources which support generic services funding will be more readily available.

These considerations influenced the National Institute on Mental Retardation to recommend that implementation of ComServ services must be a gradual and careful process. Its plan recommends an intermediate step—the establishment of a limited number of experimental* and demonstration (E&D) ComServ projects which will develop and test methods of organizing and delivering community service in various settings and types of regions. NIMR recommended that (at most) one suitable area be selected as an E&D region in each of several Canadian provinces.

General support will come only when people see and appreciate the complexity of ComServ and how much it will accomplish. E&D projects will experiment with various approaches and illustrate how such services would and should work. By demonstrating success in a series of model communities, they can serve as a catalyst for the implementation of comprehensive community services on a nationwide basis. They ultimately promote a much faster and less costly development than a sudden, ill-explored universal approach.

In summary, E&D projects will serve three major purposes:

- To demonstrate coordinated delivery of comprehensive services to retarded people within a defined community or region.

- To serve as field laboratories for the evaluation and examination of various concepts, patterns, and service challenges. Each regional service system might best test a different pattern of service and in this way ComServ will demonstrate a variety of solutions to be applied across the country.

- To serve as training grounds for people who will later staff similar ComServ regions. NIMR has been building up its resources as a training center so that it can give the necessary direction and skills to professional staff planners, people working on specific proposals, CAMR volunteers and leaders. As these people are trained and go back to their provinces with the backup support of NIMR, they will inform and educate others within the regions where they work. This is an example of the multiplying effect so important to the future development of Comprehensive Community Services.

Each of the E&D projects is intended to cover a minimum six-year experimental period—one to two years, for feasibility studies and preparation, with four to five years' implementation. Ongoing and final evaluations are also incorporated.

The E&D project may take one of three forms. The most limited form would be that in which comprehensive services would be developed and provided only for the mentally retarded. A second form would address itself to the developmentally handicapped or even all handicapped individuals. The third form of comprehensive services could be of a generic nature, where services would not be limited only to persons with handicaps but provide total services for all persons requiring assistance.

Selection Criteria

Previous experience with demonstrations in other places indicates that they frequently fail if strong direction, guidance and quality control are not instituted at the beginning and sustained throughout. If a project does fail, there may be increased resistance to future innovations. It is crucially important, therefore, that as many E&D ComServ projects as possible be successful. The ultimate test of success will be whether the project can actually influence long-term and large-scale service policy by convincing the public and its decision-makers to institute comprehensive systems across the nation.

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*The terms experimental and demonstration are used to emphasize that ComServ requires field testing before it is considered a viable plan.

In order to help assure such quality, 12 criteria have been evolved for selecting and approving any project before it is designated as an E&D ComServ project. These criteria mean that projects will not be selected primarily because new services are needed in some region or because a region is more deprived and more in need of service than most others. What must be shown is that any new services that are needed fit into a general overall plan for developing a comprehensive service system for the region, that the region is suitable in other important ways as an E&D ComServ region, and that the preconditions to a successful demonstration exist.

The 12 criteria that have been set down for selecting an E&D project fall into those determining the suitability of a region for an E&D project and those determining the suitability of the program. The six criteria for regional suitability include sufficient population size to justify a wide range of services, accessibility of a region to transportation routes, availability of professional resources in the region such as might be found in an institution of higher learning, community receptivity to the project, strength of existing consumer and related organizations within the region, and prospects of local and long-term funding. The six criteria for program suitability include a plan to offer a wide range of services, evidence of strong project direction, commitment to the demonstration role, willingness of regional personnel to accept consultation, applicability of the demonstration lesson to other areas of the country, and adoption of some specific research mission.

Personnel Needs

The development in the ComServ regions, and indeed nationwide, of a knowledgeable and able leadership, as well as of a supportive attitude base, are critical to the success of the ComServ program. Also, in the long run, careful planning as well as extensive communication and training programs will be even more important than the raising of large amounts of service funds on a "one-shot" basis.

There is an acute shortage of both staff and volunteers who are trained and experienced in modern change agentry and organizational system approaches in the field of mental retardation. Existing training programs in colleges and universities need to be supplemented by short-term training for large numbers of people.

All these workers will need to be trained for new roles and responsibilities. Many jobs now done only by professionals will be performed more effectively by less specialized frontline workers—volunteers and staff—while professionals must have more time to develop services to meet special and changed needs. In this way, there will be considerable savings of manpower and also development of human talents. The training thrust must extend to preparing new leadership in the human service program planning and implementation areas, emphasizing the dynamics of change within and between service organizations and systems.

Funding

It will usually be possible to start implementing the E&D ComServ projects with existing services and to take advantage of buildings, funding, mechanisms, and other resources which are already available.

As ComServ principles are demonstrated to be effective, fiscal resources currently absorbed by less adaptive services will be reallocated towards more constructive areas. For example, considerable program flexibility should result as money is gradually shifted from institutional to community budgets. Supportive funding may also become available from school systems which now have a surplus of classroom space and teaching staff because of declining birth rates. Educational services are less likely to exclude handicapped children than has been the case, and these children can be served in the public schools without new taxes. Indeed, many schools appear to be able not merely to include more handicapped children but further to broaden their services by extending the age-range of children taught. Thus, younger children are increasingly offered developmental day care and kindergarten programs and older handicapped ones are provided with the opportunity to remain in school longer for vocation-oriented training.

These changes may involve relatively modest or at times no new fiscal allotments. However, influx of additional moneys will also be necessary. CAMR launched a fund-raising campaign to provide much needed "seed" money for developments to date. At the same time, consultations are being undertaken with federal, provincial/state and local governments to develop the basis of long-term funding for comprehensive local services. Full advantage can be taken of existing fiscal resources to cover many of the community services. Public and professional leaders are being oriented to the importance of the commitment of at least some local (municipal, county, township, etc.) tax monies for local services. The ultimate objective is to spread the cost of comprehensive services for the handicapped across many types and levels of sources and to weld together a federal-provincial, state-local funding partnership.

One of the criteria for acceptance of a project from a region is that prospects of local fund-matching and continuance should be good. There must be reasonable evidence that the likelihood for stable long-term funding for the project is high; that this funding will assure its continuance and that the local community will participate in this funding.

Initial funding support might come from private sources, which allows for flexibility in providing services. However, in the long run, only public funding will ensure the stability and continuation of services or will indeed signify that these services are provided as a matter of right rather than on the basis of pity and charity. Therefore, the long-term goal of any E&D ComServ project must be to achieve a base by which the service is publicly mandated and therefore publicly funded. A measure of the success of a project will be the extent to which it accomplishes this goal.

Some local funding participation is highly desirable. Most of this local participation, at least over the long run, should also be public (county, municipal, etc.), but some private supplementary funds from voluntary organizations or from other non-governmental sources are also desirable.

This local participation indicates that local communities are committed to the E&D ComServ project and share in the belief that individuals have a right to basic services. Local commitment to the idea that people, given the necessary services, are capable of participating to a fuller extent in the life of the community can go a long way in developing long-term government funding because governments tend to respond to public sentiment and values.

Local funding also identifies the local population with the service program and with the previously often devalued citizens it serves. This can show the handicapped people that others are manifestly willing to have them share to a greater extent in normative community living. It can also motivate the public to take an active role in the service's governance, evaluation, etc. These effects mutually reinforce each other in the change process to benefit both the service recipient and the service supporters.

Finally, local funding provides for a built-in flexibility in obtaining the services that are most relevant to local needs.

Progress to Date

The research, concept formulation, development of materials, and launching of training programs and orientation of the Canadian constituency has absorbed much of the time and effort to date. The principal document, Plan and Guidelines for Comprehensive Community Service,[4] is in the field and proposals for ComServ are being received. One project is getting under way. It is hoped that projects will develop in sequence, each gaining from the experience of the others.

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Part V: People, Places and Change

21. Architectural Implications

H. David Sokoloff

Introduction

The new "developmental" ideology is now the accepting foundation of our service systems. Even in our worst institutions it is written into program goals.

Yet we know that there is a gap between what we would like to see and what actually happens—there are practical problems in shifting to a new pattern of services demanded by a different philosophy.

All this holds true for buildings which are components of the service system and the problems are compounded by the present planning procedures, which are insensitive to the real needs of those who will use these buildings.

The practical problems of our present situation are most clearly exemplified by the dilemma of what to do with existing buildings as we move towards change. When you are saddled with worn-out old buildings which are inappropriate to new program concepts and in which intolerable conditions are tolerated, any attempts to divert funds into new buildings and new programs elsewhere are seen both by the people with vested interest in the institutions and by parents whose children live there as a serious threat. Yet to pour money into remodeling old buildings may often do no more than alleviate the worst aspects of physical deficiencies. Refurbished gang toilets instead of worn out gang toilets; cheerfully painted wards with tightly packed beds instead of cold impersonal wards with tightly packed beds do not amount to the sort of change to which we are now committed. These are problems which we have to solve if the new ideologies are to be translated into action.

Just as much of what has happened in the past has been affected by the buildings which house our programs, so much of what will happen in the future will be affected by the kinds of buildings we create and by the process we use in developing them. Problems cannot be solved in isolation. We have in the past assumed that the building is an entity which can be designed and built as though it were no more than an arrangement of physical materials. A building is in fact just one element of a service system; that system cannot be altered successfully if the other elements remain the same, since all are interdependent.

When we remove architecture from its social context and when we separate design from the processes of service system planning, we compound the problems we set out to solve. We will be more likely to develop successful solutions if we develop procedures to manage complexity that if we oversimplify the problems. Therefore it is important to understand how the planning process translates ideas into the physical reality which is a building, and the roles which the building can and cannot play as a component of a service system.

What Is A Building?

A building is one important component of the service system. It is not a program; it is a place, a part of the environment where the program takes place. The building may either inhibit or enhance the program, but it is not a substitute. It is not much better for residents to sit aimlessly watching television in one kind of facility than it is in another.

A building used as a residential facility for mentally retarded people is in a sense a training apparatus for learning the skills required to participate and to act as an accepted member of a neighborhood and its community. It is a kind of "teaching machine" in which people learn the skills required for living.

Learning to live means learning to manipulate the teaching machine itself and its equipment—switching on lights, shutting off the gas, showering, opening doors, drawing curtains, and so on. It means developing the skills necessary to taking care of your own physical self—eating, bathing, shaving, grooming, and so forth. It means learning to manage your own psychological self—listening, getting ready, feeling the morning, relaxing, handling anger, etc. It is in the learning machine that you experience the relationships which teach you the hierarchies of cooperation and sharing, it is where you learn the rules demanded by the culture for personal and interpersonal behavior. It is where you learn who you are and who you can be.

The facility is also a teaching machine for staff and students, for parents and families, who will learn the support techniques which can be applied elsewhere, when the resident graduates to greater independence.

However, the facility is more than a teaching machine for the users; it plays other roles which affect the lives of the residents. It is a power center which commands program funds. It is an employer of labor, a purchaser of goods and services, and a taxpayer. Its power usually increases with its size, which tends to conflict with its own program goals. Jean Vanier says that the size of a "home" relates to the number of people who can fit around the dining table. Marie Tappendorf [1] used to say that she liked to know which clothes belonged to what resident.

Most of the incentives and rewards are with increased size. For the sponsors or donors there is a tangible memorial; for the administrators there is an increase in their power base combined with "administrative convenience"; for the politicians there is a visible physical result of their efforts; for the architect there is a larger project and an increased fee; for parents of the residents without other alternatives, there is an increased permanence, a greater promise of care after they themselves are no longer around.

Only for the retarded residents are the rewards in inverse ratio to size. For the facility sends messages to the residents, to the staff, to the service system administration, to the relatives of the people who live there, to the political decision makers, to the enforcers of code regulations, and to the public at large. The messages can either increase the perception of the handicapped person as a developing human being or they can reinforce his primary handicap with the secondary one of seeing him and being perceived by others as dependent and less than fully human. As they are perceived, so goes the service system.

The Role of the Architect—His Influence and Morality

A competition to design a group home would have very different winners if it were judged by a real estate developer, a sculptor, a plumber, a psychologist or a contemplative monk. The architect, too, has his judgmental criteria which must be integrated with the essential program concerns.

For the architect's influence is considerable, and often in areas beyond his expertise; he will influence decisions which create physical environments that, in turn, have social and psychological effects. The architect is often gratefully relied on as "the expert" by his clients. For instance, a school board may trust his knowledge of educational philosophy or an administrator in the department of corrections may trust his knowledge of the sociology of prisons. Sometimes, either because of training or because of accumulated experience, the architect may indeed be expert. It is not, however, reasonable to demand this expertise of him as an automatic attribute.

On his side, the architect must realize that not only does he have considerable influence, because it is he who translates program requirements into physical reality, but that he will also make many decisions which have results beyond expectations. For example, the design characteristics which might give excitement and interest to the visual environment of a mental health clinic, could be the very characteristics which tend to disorient and confuse patients; thus the building would tend to work against therapeutic objectives.

The facility is sometimes an "ego trip" for the person in charge of its development as well as for the architect. This is not necessarily bad unless program concerns are forgotten in the excitement of the development of a new physical entity. Creating a building is a very intoxicating experience, for the result is a tangible and lasting expression of creativity. It is also an expression of the values of the people involved in its development.

Therefore, the architect must be very aware of what he is doing and of the values which he brings to his work. George Gray, AIA, the director of facilities planning for the New York State Department of Mental Hygiene, commented in 1972 on the proposal to create a self-contained, multi-purpose institution for 750 retarded children in New York City:

"Architects are participants in perpetuation of immorality, which is in strange contradiction to their learned sense of understanding of how man normally functions in relation to his physical environment. The impact of going against their native good judgment, for whatever reason, being misled by glib or recalcitrant service professionals, to being crassly concerned with their profit motivation, must be brought home to them."

The issue is a moral one which the architectural profession cannot ignore if it expects to be looked to for leadership in the creation of the environment of the future.

The Roles and Influence of State Facility and Construction Bureaus

If handicapped people are to be able to use optional services which are appropriate to their changing stages of maturity and abilities, it will be necessary to make available a variety of small residential facilities in the community. The kinds of facilities required are completely different from those required by the traditional institutional system. For the most part they will be small, located in the community, and similar in appearance to facilities used by nonhandicapped people. They may be remodeled or renovated as well as new and purpose-built. They may be rented or leased as well as owned. They may be programmed, planned, and developed by a variety of organizations and individuals. Their program may be funded from a variety of sources. They may be located in a variety of areas having different geographic, climatological and sociological characteristics.

It can be seen immediately that the kinds of facilities required by a developmental system are different in quality, size, character, and intent from those which our present federal and state agencies and funding mechanisms are designed to produce.

Typically, institutional facilities have been developed by state-financed capital outlay grants for a specific project. The institution is usually one of a group of institutions whose capital outlay requests comprise a budget request of the mental hygiene or mental retardation bureau. Other bureaus in the same agency will also have capital outlay requests which are combined into the agency capital outlay budget. This is a long process, and the specific request for facility funding must first develop a high priority within its own bureau; the bureau's capital outlay request must then develop a high priority within the agency. Funding seldom takes less than three years from the time of conception and often takes much longer.

There are as yet no statewide systems to foster the development of small community-based residential facilities; each group has to teach itself how to identify local needs, search for funding, develop programs, and deal with architects, building inspectors, and contractors who know how to build institutions but not community-based facilities for handicapped people. It is obvious that with no system of procedures and assistance, even though funds are available, the development of necessary community facilities is unlikely to be either fast or efficient.

Existing state bureaus responsible for architecture and construction are usually procedurally locked into old program concepts.

It is often difficult for them to understand that the heavy-duty, low-maintenance construction with which they are familiar can work against the objectives of a normalizing system of human management. Such construction assumes that the building must withstand abnormal use; by implication, the user is subhuman or dangerous. Thus, the exigencies of physical plant overshadow the need to develop the skills of the residents.

Consideration must be given to the roles of the architectural and construction bureaus in developing facilities. These roles will vary according to the traditions, size and problems of each particular state, the scope of need, and the nature of the funding sources.

The influence of these bureaus should not be overlooked. Many will need training and rewards in order to play a positive role.

Why Buildings Fail—The Planning Process as Opportunity

Buildings often fail in their purpose even though guidelines are developed for use by the architect which are consistent with program goals and objectives. Some failures may be attributed to the length of time between the idea and the physical reality, during which people, circumstances, and program goals themselves have changed. Some failures may be attributed to the requirements of codes and standards which work against program objectives. But there is another factor which must be considered—the planning process itself.

Change under any circumstance is difficult. Often it seems easier to continue in discomfort rather than change. The process of planning, however, forces us to conceptualize future changed circumstances. For example, school design is changing in order to serve new program concepts. Schools which are to be used for team teaching, individualized programs, and flexible schedules need a special acoustical environment to allow for the absence of walls.

Teachers who have not experienced this kind of environment may be apprehensive about how they will manage. The planning process affords a singular opportunity to involve the teachers in the design decisions which will affect them when they move into the new facility. It affords them the opportunity to understand and adjust to changing methods of teaching. Conversely, then, they are denied participation in this process and find themselves suddenly in a strange and intimidating environment; the building not only inhibits attaining educational objectives but continues the inhibition long after those involved have moved elsewhere.

The lessons are plain:

- Those who will use the building have useful information to give to the programmers and designers.
- The success of the building depends in part on its acceptance by those who will use it, including staff and the residents.
- Participation in the planning process, once the building is occupied, affords a singular opportunity to conceptualize future changes.
- Those who will be affected by (planning) decisions should be involved in the decisions which affect them, regardless of the opinion of decision-makers as to their worth or their competence.

Because of these considerations, the architects should use their considerable influence to encourage the participation of the users, including the handicapped themselves, in the planning process.

Transitional Facilities

Many states are committed to the development of a community system of programs, services, and facilities to replace those state institutions which have deteriorated and which cannot be adapted easily and economically to modern program requirements.

During the period of transition from an institution-oriented system to a community-based system of services and facilities, it is necessary to create acceptable living environments for mentally retarded residents who must remain in state institutions while appropriate services and facilities are being developed in the community.

Remodeling old institutions is appallingly expensive. In Pennsylvania in 1971, a proposal to remodel two wards at Pennhurst State School and Hospital would have cost $36,726 per resident (between five and six times the cost of single family suburban housing). A state report commented: "This is an incredible renovation cost . . . and the buildings still do not meet modern program standards after renovation."[2]

This poses the choice of either forcing people to remain in intolerable conditions in order to finance the community system, or diverting money needed to build the new community system to shoring up the old institutions. The usual result of this universal dilemma is satisfactory to no one except perhaps some legislators who use this split constituency as an excuse for funding as little as possible.

The problem is not whether state institutions or community services and facilities are the better solution, but how the many partners of a single, comprehensive, coordinated service system can interrelate and be sensitive to the needs of all those who are developmentally disabled, regardless of whether they have the potential for living semi-independently in their own community, or whether they need 24 hour nursing care to stay alive.

One possible solution to this dilemma was suggested by the development of low-cost, factory-built, transitional residential facilities to be financed over a 10-year period. This was proposed to the Commonwealth of Pennsylvania's Department of Public Welfare, and in 1973 a feasibility study[3] was prepared.

The "transitional facilities" were to be comprised of specially-designed, factory-fabricated units, transported to the site, where they would be placed on permanent foundations and joined to make single houses, each for eight residents. Decks, porches, exterior wall, and roof treatment were to be added after the units were in place in order to give the appearance of well-designed conventional housing.

Transitional housing has many advantages; it can be developed in six months in contrast to conventional institutional buildings which take a minimum of three to four years. It avoids the zoning problems often encountered in communities by being located on state-owned land. It need not adhere to the Uniform Building Code which regulates conventional construction (but must conform to the manufactured housing codes).[4,5]

It is comparatively inexpensive and thus diverts only minimal resources away from the development of community-based services and facilities. Costs in 1973 were estimated at $6,000 per resident as compared with $25,000 to more than $40,000 per resident for typical institutional construction in Illinois, Pennsylvania and New York.

One serious objection to such a system is that "temporary" housing tends to become permanent. The critical question is whether, through legislation or through legal means with consumer watchdogging, it can be ensured that the housing is in fact removed after a 10-year period.

It would seem to be worth risking a future which is not preordained in order to alleviate immediately intolerable conditions which are fixed.

The Message of Codes, The Danger of Standards

Many handicapped people will at some time in their lives need out-of-home residential care; the manner in which we provide this care helps determine society's attitude towards them. If their living arrangements are different from those used by other people, they will be considered "different" and will find it more difficult to be accepted as neighbors or as citizens. Fewer perceptible differences increase the chances that handicapped persons will be considered human beings with rights.

At present, the building of new facilities or remodeling of existing ones is inhibited by the very building code and life safety code regulations which are intended to protect the resident.

"The urge to overprotect invariably squeezes the life out of any good expectations one might have for a person who is retarded; and when expectations for a person are low, his feelings of being no good are reinforced, while his urge to make his life count for something good can slowly be diminished."[6]

These regulations involve special plan arrangements, special exit requirements, the use of special building materials and special construction. The resulting "specialness" of the building accentuates the handicapped person's "difference" and adds another stigma to an already difficult life.

Those who set policy for safety restrictions and those who administer the rules and regulations enforcing policy are interested not solely in safety. They are understandably concerned with their own legal and moral liability in case of accidents. Officials want to be sure that no one comes to harm because of weak regulations or lax enforcement.

It is unreasonable to ask public officials to make special allowances for handicapped people so that they can be afforded the dignity of risk-taking. There are solutions that will exempt them from this kind of liability, give proper protection to handicapped residents, and at the same time minimize their "differentness." For instance, it would be perfectly possible for life-safety experts to assess the amount of time it takes an able-bodied person to escape from any part of a building. This "escape time" would be related to the plan of the building, to the combustibility of its materials, and to the type of construction. For example, a particular building could have a designated "escape time" of two minutes. Anyone, regardless of their handicap, would be allowed to use the facility provided they can pass an "escape test."

Passing the test would involve training, practice, and a time trial. Retesting might be required at intervals to ensure continued safety and competence, particularly in the case of increasing age or a deteriorating condition. This system would protect public officials since "escape time" would be set conservatively and licensing tests would be realistic. The present system assumes the permanent incompetence of the handicapped and publicizes this assumption, whereas this method would emphasize the expectation of improvement and success. The psychological impact of success in passing the test, combined with the reward of being allowed to live in a more "normal" facility, would improve not only the self-image of the handicapped person, but also the perception of him held by others, including those responsible for the test, those who serve him in a staff capacity, those with administrative responsibility for him, and the general public.

Code adjustment, however, is in good part a political problem sensitive to thrust from above rather than below. As a result of a meeting sponsored jointly by the United Cerebral Palsy Association and the National Association for Retarded Citizens in San Francisco, the President's Committee on Mental Retardation commissioned the formation of the "Ad Hoc Committee on Codes, Standards, and the Developmentally Disabled." The committee, made up of members from 26 national organizations, addressed itself to the systematic analysis of problems and to the development of proposed solutions.

Standards have traditionally addressed themselves to physical requirements, such as sizes of rooms, numbers of toilets, amount of ventilation, etc. Compliance with required physical standards does not automatically guarantee program adequacy. The combination of program and facility standards developed by the Joint Commission on Accreditation of Hospitals[7] has moved a long way toward relating standards to objectives. But there are difficulties; one cannot enforce what is not specific, and yet what can be made specific does not guarantee desired results.

One response to this problem has been the thrust to toughen enforcement by incorporating the J.C.A.H. standards into Federal legislation. This is a dangerous course, which could result in the standards working against program goals. Goal-related principles need to be incorporated into legislation, but standards must remain flexible so that they can be constantly reviewed, modified, and adjusted. Once standards become law, change becomes very difficult; so difficult that it is often easier to work around the standards, to look for loopholes. Their real purposes are often distorted and only remembered dimly. Our cultural style is to pile restrictions upon restrictions until the overall complexity and the interdependencies make it difficult for those with jurisdictional authority even to affect the areas of responsibility, let alone control them.

In one large Eastern state the combination of codes, regulations, and required agency clearances has made it impossible to install toilet seats in seven state institutions. So we find people of good heart, competent people in positions of authority, unable to get toilet seats installed for the comfort and dignity of the retarded residents whom their jobs were created to serve!

In many states the unwieldiness of funding procedures virtually ensures the development of obsolete, unnecessarily expensive buildings which perpetuate inappropriate treatment modes.

These funding procedures often give a measure of control over design to the state finance bureaus, which means that the bureaus are in a position to affect the nature of programs and facilities in which they have little interest beyond that of costs.

State finance agencies can ignore or overrule program and design considerations which are of concern to both client and architect, since they can often designate specific cost reduction items after design is completed. If the architect happens to be an employee of a state bureau, his power to advocate his clients' concerns is even weaker than if he is in private practice.

A model system of building design and development which could be useful in developing facilities for mentally retarded people has been used successfully in California for more than 25 years to build schools for impoverished school districts.

School districts already bonded to the legal limit have been able to apply for an entitlement of "square feet" to house their projected enrollement increase.

They may use this space as they choose within acceptable educational standards. After design is approved, money is allocated to the project by a continuously adjusted formula which ensures an architectural quality demanded by the state for its investment. This system effectively limits the influence of the department of finance to the amount of money available. It also ensures local response to local problems and the flexibility to meet new technological, managerial, and educational developments.

Perhaps most important of all, it has prevented the duplication of models geared to inappropriate program concepts during a period of rapid change. If buildings are to represent a wise investment of public funds, standards of quality must be related to program effectiveness. Clearly, construction costs must not be higher than is necessary, for that would be extravagance. But if quality of materials and amount of space are set too low in order to save initial capital spending, not only will maintenance and repair become excessive, but the incidence of future remodeling will be increased.

Most important of all, however, the design of facilities must afford the greatest possible efficiency in the use of staff. The importance of economical staff utilization becomes apparent when a sum equal to the capital outlay cost of a building is spent in three years of operation for staff salaries. If, for example, the cost of a residential facility is $15,000.00 per resident and the staffing cost $5,000.00 per year, it can be seen that a reduction of 1 dollar in initial cost which may decrease staff efficiency, can adversely affect 10 dollars worth of staff salary over a 30-year amortization period.

Initial capital outlay cost is not an adequate measure for planning purposes. Real cost consists of the cost of land, total construction cost including furniture and equipment, the cost of fees, inspection, site and materials testing, the cost of debt service, the cost of maintenance and repair, and the cost of utilities. The total of these costs divided by the number of residents, divided by the number of years of amortization gives the cost of the facility per resident per year. To this can be added program cost. It is against this figure that cost-efficiency decisions should be made.

Conclusion

The manner in which we provide residential care helps determine society's attitudes towards retarded people. The facilities in which people live affect the way in which they spend their time and their relationships with others.

The service system is moving away from the use of large, segregated "care" facilities toward a variety of small, community-based, "developmental" facilities. The application of the new principles has often been very uneven. Broad societal changes which affect handicapped people are often ignored when we plan new programs and the facilities they require.

Architects and planners are often aware of these changes, but they have not allowed their designs to reflect them; they often limit their interest to physical considerations like the size of rooms, structural systems, and material costs.

But design is the introduction of intent into events. Even the architect, whose knowledge of the present changes is limited, is still the filter through which information is interpreted into building design. The architect has great influence on the future because of the role he plays in creating the shape of the facilities in which the new program concepts will shape the lives of retarded people. Architects must, of course, operate within the prevailing value system; the question is, however, how far they can lead and how far they must follow.

The present developmental ideology and the principle of normalization on which it is based are the goals of our traditional value system, a system in which people are valued by success—particularly economic success—and by their ability to fit into the existing patterns of society. The virtues particularly valued in this system are self-sufficiency, independence, individuality, rationality, pragmatism and orderliness. These are characteristics in which mentally retarded people are usually somewhat weak.

We are, however, moving into a time when change itself is the primary characteristic of the environment and when these traditional values are changing. There is a shift from concern with inability to manipulate the environment to concern with problems caused by the very success of technology. We are moving away from viewing logic and language as the perfected instruments of intellectual analysis and expression and towards the realization that the way our senses report experience is structured by the conventions of art, language, and the media. We are shifting away from a hierarchy of values which accepts that some human activities are worth more and should be better rewarded than others, toward a spectrum of values which suggests that all human activity has potential for greatness. We are moving from a faith in rationality toward a sense that the scope and potential of the unconscious is essential to a new image of man. We are moving, essentially, from materialistic and status values to more humanistic and spiritual values. The characteristics admired in this new value system are openness, authenticity, spontaneity, honesty, simplicity, trust, and interdependence. These are characteristics in which retarded people usually excel.

In this changing situation, the architect has great influence. As a physical designer, he is also a social designer, and society looks to him with respect as a professional involved in the shaping and the creation of the future. He is often a key intervention agent in the planning process; if he is sensitive to the issues, he can be an agent of constructive change.

Special efforts to educate "leader" and future "leader" architects in what it means to be handicapped and the needs and perceptions of those we define in this way should, therefore, be made by architectural school faculty members and those involved with architectural publications.

"If I am not for myself, who will be for me?

If I am for myself alone, what am I?

And if not now, when?"[8]

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Biography

H. DAVID SOKOLOFF was born in London on March 31, 1920. He received his education at the Sorbonne University, Cambridge, and Yale. He served as a pilot in the Royal Canadian Air Force during World War II.

Mr. Sokoloff is president of Sokoloff, Hamilton, Bennett, AIA, and serves as a consultant to several colleges, universities and states. He is also a member of the State Developmental Disabilities Planning and Advisory Council. He is co-author of the book, *Communicate*, and author of *Transitional Facilities—A New Concept in Meeting the Needs of Mentally Retarded People Living in State Institutions.*

22. The Caring Staff

Ann Shearer

We are fortunate, at the moment, to have a good number of people in our university departments and academic institutes who not only devote a fair amount of time to analyzing what has gone wrong with our residential care in the past but who put a good deal of energy into working out new patterns for the future. We are fortunate, at the moment, to have legislatures and executives who are responding to the pressure on them to help make new ideas a working reality.

But in our enthusiasm for the new structures that look to be such an advance on the drawing board, we are perhaps in danger of forgetting the contributions of the very people whose deep and continuing involvement will be essential if those structures are to become real and to grow. It is they, after all, who are going to have to make the new theories work and who are going to facilitate or to hinder the growth of the handicapped people all this energy is meant to benefit. They are also the frontline guardians of standards and the mediators between the new community residential homes and the wider community of which we hope they will be an integrated part.

It is particularly important that we look carefully at what we expect of and offer our caring staff now, when our aspiration is to make the local community the pivot of residential care. A residential home may be small both as an administrative unit and as a physical environment, and yet still not come near to offering mentally handicapped poeple the chance to grow in security and happiness. A small administrative unit can be shut away from its immediate community; its staff may feel more isolated than in institutions with many similar units on the same campus; it may become harder to safeguard standards than in institutions where at least the population is clustered on the same site. A residential unit may have delightful furnishings and impeccably private bathrooms but may still almost completely lack what any of us would consider the spirit of "home."

A recent British study (King, Raynes and Tizard)[1] has tried to measure what makes up "good" residential care for children by looking at patterns of child management in mental handicap hospital units and hostels and in homes for deprived and mentally handicapped children. It found that "child-oriented" or "institution-oriented" care had nothing to do with whether a child was mentally handicapped. "Indeed, the mentally retarded children in the hostel and the voluntary home led lives which were very similar to those of the deprived children in the children's homes. In these units, the children were accorded respect as individuals; they had opportunities for both privacy and companionship, for personal clothing, and for a share in the possessions of the community; they lived in an environment where rules were few and exceptions to them readily made, and where the staff were friendly and had an opportunity to get to know them. In these units the staff worked for long periods of time with a single group of children. In the hospitals, the needs of young children for affection, for individual treatment, for variety of experience, and for continuity of relationships received little attention. Treatment was not harsh or cruel, but the environment was bleak and the atmosphere institutional."

The difference between the two sorts of care is clear. But it did not, the study found, depend decisively on the size of unit or the size of the institution of which the unit was a part; reducing the size of units does not, of itself, change the pattern of care.

Nor does hiring extra staff. We all know that eight staff members can sit and drink coffee in the staff room just as easily as two—in fact, it may be even more enjoyable for them—while mentally handicapped people are deprived of their company and encouragement. The study just quoted confirms what common sense tells us; it found that a large number of staff does not, of itself, guarantee child-oriented care (although the child-oriented establishments it assessed did have more staff on duty at "peak" periods than the others).

So we begin to unravel the components of the residential care we want to see and we find that the features we most commonly demand—small size, decentralization of administration, high staff-resident ratios—are not, of themselves, enough. We may feel more comfortable when we deal with these easily-measured components than when we enter the harder to cope with areas of relationship between carers and cared-for. But it is inescapable that we must. And that in turn demands that we recognize the needs of caring staff.

If we do not, the fine intentions of our new systems will be in danger of failing, just as the fine intentions of the founders of our large retardation institutions collapsed into insensitivity and neglect. The handicapped people in our new residential homes will not find the emotional warmth and encouragement to growth they need. King, Raynes and Tizard found, for example, that children living in "child-oriented" units had more developed speech and eating skills than those in "institution-oriented" units. It would be hard to reject their suggestion that this was because staff in the first sort of unit spent more time in talking to and interacting with children, including sharing meals with them, than staff in the second, who were busy with "chores" and ate separately.

Unless we can find ways to encourage staff to make our new residential units "resident-oriented"—and we will look later at some of King, Raynes and Tizard's findings on essential components—we are in danger of seeing the collapse of our aspirations for the growth of handicapped people. We have to find ways to encourage staff to stay in the units long enough to ensure both administrative stability and some continuity of relationships for handicapped people. On a sheerly practical level, there will not be the possibility in small local homes of simply transferring staff from another unit that there is in the large institutions.

Staff are, at the moment, often left out of the planning process and offered simply a routine which other people have decided they should follow. They are often not consulted about changes which affect them and the people they may know better than anyone—the handicapped people for whom they care. They are blocked when they try to act as advocates for the handicapped people. They are, in short, made to feel that they do not matter. And what would most of us do if we felt devalued? We would either stop trying to contribute, and simply carry out the minimum work so that we could pick up our pay; or we would look for another job and leave; or we would stay, in growing resentment, and kick the man below us in the pecking order—the handicapped person in our care.

This is not to see all caring staff as ill-treated and misunderstood crusaders for the rights of handicapped people any more than it is to see all members of management and planning teams as insensitive self-aggrandizers. Of course, there are staff who are, quite simply, completely unsuited to work closely with other people and should never have come into this business at all. Of course, there are members of management who wear themselves out in the face of solid staff opposition. But the question must still remain: how do we care for our caring staff? Why is it that staff become uncaring or just leave?

Certainly, residential work is tiring and daily and demanding. But what we have to ask ourselves is how far our patterns of residential care support and encourage the staff to find fulfillment through all the inevitable frustrations. In another chapter, we examine the contribution one organization, l'Arche, tries to make to this question in the way it cherishes relationships between assistants and handicapped people as a central element in its work. Here, we will look at some of the different ways in which staff can make their contribution to change—and, as important, the ways in which our patterns of care can block that contribution.

Staff as Innovators

"Good" residential care is not easily quantified. Certainly we can attempt to isolate elements that distinguish, as already quoted, "child-oriented" rather than "institution-oriented" care; we can observe components of what seem to be closed, unhappy situations and contrast them with what seems to make up an open, growing one. But the interplay of individual needs, strengths, and weaknesses among the residents and staff who make up a group is finally something which defies particular prescriptions. The dynamic of change is a delicate one that depends as much on what is being fed upwards from the people living the daily reality as on what is being fed downwards from the people who have charge of the overall orientation.

In this sort of situation, it seems only reasonable to expect that the running of residential units should reflect a cooperation between the people "in charge" and the people at ground floor level. Growth would seem more likely to come by exchange, discussion, and mutual encouragement between these different levels than by either the dictation of a policy, which may sound good but is actually impractical, or by a lack of a policy, which leaves caring staff muddled and frustrated. And yet what happens? Staff in the front line of care are often not encouraged to have ideas, but simply to carry out the ideas that other people have had.

This lack of encouragement to caring staff has been noted time and again, together with its effects. The Hospital Advisory Service, for instance, which in England acts as a professional advisor to long-stay hospitals, gave these examples of situations its teams met during the course of a year:

"The teams have repeatedly noted that delegation of authority to nurses at ward level often leads to very significant improvement in patient care. Teams have seen nurses who take an active part in social training help to place their patients in suitable situations in the community and run an effective follow-up service for their patients. On wards, morale is often significantly higher where the ward nurse has a major say in the pattern of care in the ward, the ward design and decor, and the right to make relevant decisions for individual patients. . . . We have seen the benefits which follow when changes are planned and agreed between all those involved and, in particular, with the ward staff concerned. At one hospital, for example, the effect on morale was obvious when some physical alterations to the ward were agreed, following meetings at ward level between doctors, nurses, and others concerned. This can be contrasted with the ill will which followed at another hospital where some partitioning was decided between the senior staff without any effective consultation or agreement at ward level." [2]

Staff must clearly feel involved if they are to make proposed changes work for the benefit of handicapped people. It is only when staff feel they matter, too, that they will begin to initiate changes themselves. One English "action research" study looked at the very important area of cooperation between different disciplines to improve the care offered to handicapped people. A preliminary stage was collecting views and information from staff at all levels. In one hospital taking part in the study, these included the hall porter, the biochemist, the records officer, the occupational therapy and laundry staff, nursing assistants, and industrial training staff. "By far the most common response is—'Thank goodness, at last someone is asking us!'."[3] the coordinator of this questionnaire noted. It was from this feeling that their views really mattered that the project started to identify areas where people with different skills could cooperate to the benefit of handicapped people.

The principle of participation does not matter only to caring staff in the front line. Clearly, unless the people over them feel that their initiatives will be valued, there will be little chance of this feeling spreading downwards. King, Raynes, and Tizard found that one of the factors which did have a lot of influence on whether a unit was child or institution-oriented was the degree of autonomy of that unit. The ones where the head had a high level of responsibility were ones with child-oriented care.

Examples of encouragement, or its lack, to the initiative and responsibility of staff tend to come from the large institutions, because this is where hierarchies are most firmly established and where, after all, we have had many years to observe patterns of care. But there is a danger of our community-based residential units falling into the same depressing pattern unless Boards of Directors are sensitive to the needs of the directors of their establishments and trust them to run those establishments with a high degree of autonomy. Only then will directors, in their turn, be able to support and encourage their staff.[4]

Staff as Advocates

Very often, it will be the caring staff, as those who are most constantly with the handicapped people, who will be able to make the most valuable suggestions on what could best help them grow. Using their insights depends largely on establishing the sort of situation of exchange and confidence indicated above. Indeed, if that sort of situation does not exist, we are likely to lose one of our valuable sources of advocacy for the individual handicapped person; how many members of the caring staff, after all, if they feel no one values them, are likely to value the handicapped people enough to promote their interests?

There is another and important level at which caring staff can act as advocates for handicapped people, and that is when the situation in the residential establishment has gone badly wrong and needs intervention from outside if it is not to become a disaster for the residents. This is a very important role for the caring staff. The handicapped people in their care may not—and often do not—have relatives or outside friends. They may be incapable of complaining about the situation for themselves. Even if they do have friends outside, these may be intimidated by the thought of the possible repercussions on the handicapped person; this is the situation, for instance, of very many parents. Until more formal systems of advocacy have been established—and even then, for who is to guarantee the emotional and professional commitment of a formal advocate?—staff will have a very important role in standing up for the rights of the people they care for.

We have seen in another chapter what happened when two members of staff at Willowbrook State School in New York took their grievances to a television company. Often, however, complaints by staff on behalf of handicapped people can only come to light through official enquiries and after much suffering.

Three major government enquiries in England in recent years have all shown the same pattern. Staff have tried to complain on behalf of handicapped people and have been victimized to the point of dismissal from the service. In the first, two nurses were "obliged" to leave after they had made complaints to the hospital authorities about ill-treatment of residents. The first, after his allegations had been dismissed by the authorities, had his term of duty changed in a way that made it impossible for him to stay at the hospital. "We feel bound to regard the story of (his) resignation," the Committee of Enquiry noted, "as symptomatic of a situation in which members of the nursing staff who were generally concerned about conditions in the hospital must have come to feel that it was almost more than their professional life was worth for them to voice any feelings of concern." The dismissal of the second was, the committee said, "a plain case of victimization"; the fact that it took place while their inquiries were going on shows perhaps how far from acceptable the standards of the hospital had become.[5]

The second enquiry was set up after three nurses from the hospital had been convicted on charges of ill-treating patients. The committee found, in its general inquiry into the state of the hospital, that the nursing staff fell into "two incompatible groups. The one, toughminded, experienced and in control. The other, younger, new to the hospital, and at the bottom of the nursing hierarchy. We were told by members of the second group that they were laughed at by ward staff when they complained of ill-treatment; that senior staff ignored their complaints because they had no corroborative evidence; that (the Chief Nursing Officer) did not seem to believe them; that they were told they were too sympathetic; and that it was a waste of time complaining."[6]

The third enquiry was set up after two nurses had been convicted of stealing residents' money and another had been convicted of manslaughter. Student nurses at the hospital in question had been complaining for about five years about their own training and the condition of some residents. Yet again, nothing had been done. The Principal Tutor told the Enquiry: "There was a persistent feeling through all the staff on this, if you brought anything to light, if you dared to step out of line by doing things, then you stood on your own two feet and took the consequences."[7]

In each of these hospitals—two for mentally handicapped people, one for the mentally ill—situations of ill-treatment and neglect could have been alleviated years before the enquiries brought them to light, if staff who wanted to complain on behalf of patients had not been intimidated into silence or if there had been proper machinery for hearing their complaints.

Again, these examples all come from the large institutions. But again, we have no guarantees that community-based residences will not run the same dangers of ill-treatment and set up exactly the same sort of methods of protecting themselves from complaint. We have heard enough, for example, about the situation of elderly people in residential homes in certain states of the U.S.A. to be not at all confident that geographical siting near centers of population will alone guarantee the new residential homes freedom from abuse.

Staff as Community Contacts

Caring staff will be an important front-line contact with the wider community. And yet they quite often feel themselves intolerably isolated. They are isolated, perhaps, by the distance of the home they work in from their own community. They are, perhaps as important, isolated from the company of professional colleagues with whom they could build up a relationship of mutual support. One residential worker reacted to a training course like this: "I now know that most residential workers feel just as isolated as I felt." Another said: "It is enlightening to know that all disciplines share the same problems and that my problems are far from being an isolated case."[8]

Very often, the most constant contact of staff with the community will be with the parents of those they are caring for. Again, there seems to be little in the organization of our traditional residential care to help this contact become anything but painful to both sides. One member of the same training course said of a meeting with parents during the course: "Despite the fact that of all the members of the group I have had most contact with parents of the mentally handicapped from my previous job, I still had a lot to learn of how deep in distress and problems of acceptance they were, even after many years. It was important to me to be reminded of this, as once in the hospital situation it is easy to forget."[9]

Just how hard it can be for staff in traditional institutions to remember is illustrated by this comment from yet another Committee of Enquiry into an English institution: "We find that parents who are critical of the way their children are cared for are resented by many of the nursing staff and indeed by some of the medical staff. The attitude is prevalent: 'If they can't manage their child themselves, why criticize us when we have so many more to try to care for?' " This has on occasions led to nurses saying: "If you don't like it, you can always take him (or her) home."[10] This sort of reaction may sound hard. But, given the situation in which caring staff so often find themselves, is it surprising?

Support for Staff

Support for caring staff can take many forms. One 2-day discussion on staff needs yielded no less than 18 different pointers to the ways in which those working in community residences could be helped to care. These ranged from the paramount need for staff to be closely involved in the running of the home and the decisions which affected them and residents to the importance of finding resources and strengths from outside the home itself.[11]

Certainly there will be some "formal" measures of support for staff. After indications of the extent of victimization of staff and others who tried to complain about the situation of residents, for instance, a government committee was set up to look at the whole question of complaints procedure in English hospitals—primarily complaints by patients in short-stay hospitals, but also by those in long-stay ones and by the staff in both. Its brief was to draw up a Code of Practice which would, as far as possible, protect all parties and ensure that complaints were fairly dealt with.[12]

But this, in a way, is a "backstop" solution. Support will come first in the creation of forums where staff can freely discuss their own reactions to the caring situation and where they can call on outside help for counselling and guidance. It will come in links forged with the wider professional community to break down through meetings of information and discussion the isolation that so many workers feel in small residential units. It will come through encouragement—and if necessary, help—to form other relationships outside the caring situation; it could be good, for instance, for residential homes to make available to staff a physical place where they know they are welcome and cared for during days or weekends off.

Most of all, support will come in the way the residential home itself is built into a real caring community rather than seen as a hierarchical setting where very few people make decisions and rather more carry them out. Unless all the staff feel deeply involved in the caring situation and respected for the contribution that each can make, it will surely be inevitable that the handicapped person suffers from being at the bottom of the hierarchical ladder.

Creation of this community will happen through meetings, regular and expected as part of the fabric of the life of the home, where information on its direction is exchanged and discussed. There will also be meetings where decisions are made and at which all members of staff—and that includes janitors, cooks and other helpers—will be truly encouraged to contribute. There will, finally, be meetings more specifically designed to help the handicapped people, where all staff involved are again encouraged to share and to learn from outside helpers, like the psychiatrist who acts as consultant to the home.

This building of a caring community is not easy. Studies of therapeutic communities—and significantly these have been pioneered in large institutional settings, which is answer enough to those who say that this sort of approach is only possible in small community homes—show how much pain there is for those at the top of the ladder in shedding their "protective omnisciences" and those further down in growing to play their full part in the working of the whole. Yet at the same time, the studies show just how much value there is for all the staff and for the residents when this sort of effort is honestly made and worked at.[13]

And it is here, perhaps, that training for staff should be oriented. A recent exercise in England—called significantly *Training for Change*—set out to discover "which methods of training are best suited to the purpose of reorienting existing care staff, whether hospital-based or not, towards modern concepts of residential care." [14, 15] Three different courses were set up for community-based and hospital workers with mentally handicapped people and others in residential care. Each was different: one concentrated on putting across new professional knowledge, another almost entirely on building up interpersonal relationships between participants, while the third combined the two approaches. The evaluation of the course found that the greatest needs of staff were precisely in this area of interpersonal skills and the tackling of organizational problems; the factual material on advances in residential care was less important and could be as easily provided in other ways. (This is not to say that professional orientation is unimportant. King, Raynes, and Tizard, for instance, found that child-oriented units were ones in which the head of the unit had been trained not in mental retardation but in child care.)

An important finding of the evaluation was that people learned not from formal teaching sessions, but first and foremost from the wealth of experience that each brought to the course; the purpose of future courses should be to help people learn how to learn from each other, whatever their formal status and role.

Here are some comments from the very mixed bunch of people—mixed in rank and training—who attended the courses, taken from their own evaluations when the courses were over:

Of their colleagues: "I am able to approach them more directly and talk to them more honestly and frankly and encourage them to do the same."

"I now see people within other disciplines as individuals, rather than stereotype them into groups."

"It emphasized that all staff, no matter how junior or senior, have a lot of creative ability that as a manager I must use to the best possible effect."

Of their work: "I feel more confident about my work as I know that I am not much more in the dark than seniors in the hospital, so I am more ready to take the plunge and do things my way. I also feel that I can do much more for the pupils because I am not so concerned about the criticism of others."

Of the handicapped people: "I think I have become more aware of the fact that there is a tendency to set inappropriate limits on a mentally handicapped person's capacity for growth both socially and emotionally."

"My family has become more involved in my work. I am gradually throwing open my doors to my residents so that whether on or off duty I am at home." [16]

Would staff members have been able to say the same of the handicapped people they cared for if they had not also been able to see each other as they did? If they are to fulfill their important job with the handicapped person, they must surely be enabled to feel confident that they are cared for themselves.

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23. Professionals and Parents

Robert Kugel

It is instructive to compare the positive assistance which parents get in coping with, for instance, diabetes or leukemia with the lack of help they often get when they have a mentally retarded child. Diabetic children get a great deal of help—medication, diet, special camps, educational programs, etc. In time, the parent and the child usually become well adjusted to this disability. If a child has leukemia, the whole family usually receives exemplary support from physicians, social workers, nurses, clergymen, friends and relatives throughout their suffering. Professional people, given the understanding that their role must be supportive, usually respond magnificently. Yet part of the anguish for families with a retarded child is that parents are often advised by professionals who offer inadequate, incomplete, or perhaps even no positive information or guidance.

People who are concerned with counselling, on whatever subject, soon become aware that needs vary markedly between families and at different times. The need may be different if the child with the handicap is the first or the last in the family, if the couple is young or more mature, if the child has many medical problems or few, or if the family has other problems, either physical or emotional. All of these problems must be understood and carefully weighed.

Early Counselling

There has been a great deal of discussion on when parents should be told about their child's handicap when this handicap is evident from birth. I suspect that the "when" is less important than the "how". Parents often say they were overwhelmed by too much information or that they were asked to make decisions about the child far too early. Above all, parents have felt abandoned by their physician, friends, and relatives in this moment of crisis when they are confronted for the first time with the statement that their child, in some fashion, is different.

Some physicians, nurses, and social workers have overlooked the fact that any deviation from what is considered normal can seem a crisis to the parent having to think about it for the first time. Even an extra finger may be enough to cause some people to reject their child. One of the early responsibilities of the counsellor is to understand the impact which his information will have on the family and, at the same time, to recognize that no matter how well he explains the situation the first time, parents must always have a second chance to discuss the nature of the problem. Surely we have all known what it is to be in a state of such anxiety that we simply have not understood or even remembered something which had been said.

In other situations where the diagnosis is not or can not be made immediately in the neonatal-period, the situation is probably very much the same. Whenever the information is first imparted, time must be given for the full implication to be perceived. This is true whether the child is five days, five months, or five years old. Counsellors also need to bring in someone else to talk to the family, partly because the information is so overwhelming and partly because it is easier to talk to some people than others. People are, for instance, often reluctant to admit to a doctor that they simply do not understand what he is talking about.

Counselling parents includes being able to offer them information on what services are available in the community. Physicians, public health nurses, social workers, and educators must all be aware of the existence of special clinics, special hospitals, day-care programs, educational opportunities, vocational training centers, and so on. The point seems obvious, but too many parents have been "guided" by professionals who know nothing, or very little, about available services and give an unnecessarily bleak and depressing picture.

Counselling also means wanting to help the parents through whatever crises they may have. Parents must know, for instance, that physicians are ready to help, whether with taking care of the child during an upper respiratory infection, which may be frightening enough for young parents even with a perfectly normal child, or with potentially more serious situations.

Counselling, finally, means that someone is ready to listen at any time. Many parents have received great help from the sympathetic ear and firsthand understanding of other parents. This is true for any type of handicapping condition and the counsellor must know how to make immediate contact with parent organizations.

Home Education

We take for granted the normal child who gets his education at home in a whole host of subjects. But this is not always true of the child with some type of handicap. Parents frequently misunderstand the nature of the handicap, believing that the child is very different. They need help to understand that the child is probably more normal than not. He, too, will have many needs which are no different from those of any other child, such as learning to sit, stand, eat, and be toilet-trained, as well as learning about his own particular environment, whatever that may be. Once parents begin to understand that they are able to help their child with many self-help skills, some of the bunden of the unknown begins to dissipate and with it some of the burden of guilt.

Most authorities would certainly argue for early stimulation for the young child, like bright objects to look at, the opportunity to hear the sounds of his environment, and being taken out into the family's world. These aspects of care do not demand special equipment, but many parents often do need some urging to provide them because they feel their child is "special" and forget that he also has ordinary and expected needs.

Too often, counselling is given only to the mother and not to the father, and too often in an office rather than on home ground. The extent to which counsellors make the effort to visit families at home during the evening may spell the difference between success or failure in efforts to help the parents and the child.

All parents need some time away from their child, whether he has a handicap or not. Babysitting arrangements and perhaps respite fostering, as well as holidays for the child with a handicap, will be important elements in the overall help offered the family.

Finally, if families are suffering also from the many problems of poverty, they must also be offered efforts to solve these. Clearly, the entire family situation, and not just the particular problem of the handicapped child, is important when we are talking about mental retardation.

Preschool Education

Nursery school education designed around the child's particular problem is often helpful and is also an opportunity to integrate the child with more "normal" children. This helps the child's development and, at the same time, can be used to help the parents understand the many aspects of their child's development which are normal, as well as those which are not. In this way, they see the child before they see the disability.

The School

One of life's big steps which all children must take is that of leaving home for some type of school situation. Just as there is a problem around the first contact a parent has with a counsellor, so can there be a problem of conveying this information to school authorities. Unfortunately, some parents wish not to disclose information, which makes the task for the school more difficult, and there may be other problems in trying to give medical and psychological information to the school. These interdisciplinary problems throw up such significant barriers to adequate care for the child and his family that the professional people involved have a special responsibility to learn how to communicate with each other. Too often failures of interprofessional communication are passed on to parents who find this impasse bewildering and upsetting.

Support During Adolescence

In our society, adolescence is a difficult adjustment for everyone—individual, family, school, and community. But for the person with a handicap, there is the additional problem of uncertainty about what life will mean later on. Mentally retarded people need information and guidance, not only on the biology of the situation but also on what it means to live as an adult.

Parents also need some special help at this time. They may have fears which are in many ways no different from those of other parents. Will the child know how to cope with his new-found sexual feelings? Will the world come to accept him? These and many other problems need sympathetic understanding from the counsellors and friends who have supported the family up to this point. The stresses of this time may also bring back old problems which had seemingly been tucked away for all time. The issue of independence becomes a problem which needs special care, and the soon-to-be-adult child and his family need help to work through their feelings.

Special Expenses

There are many programs which assist with aspects of special care; funds are often available, for example, for a hearing aid or an artificial limb. Unfortunately, funds are frequently not available for certain other expenses. The family which must travel some distance to bring their child to medical care is seldom provided the money for this added expense, nor is the family which must make many visits to different specialized centers within a city. The expenses of transport are real, but they are seldom included in the total cost of maintaining the child at home. This is a situation which often requires the aid of enlightened parents and enlightened counsellors, so that together they may find ways of solving these problems.

Conclusion

Sensitivity to the needs of people is probably the key to successful counselling at any level, together with knowledge about resources. Those who take on the task of counselling in an effort to help parents keep their child within the community embark on a long series of efforts. The course is seldom the same for any two families and, consequently, the approach must be individualized at every step of the way. It is not enough to make plans for programs in the community and to leave out the vital question of parental and family support. Even the best of programs cannot help parents if the parents are not ready to accept the services.

24. The Handicapped Person

Ann Shearer

A teenage girl is writing an essay about Down's Syndrome. She knows a bit about this because it is what her young foster has. "There is something in me," she says, "that causes me to pity abnormal children to the point that I sincerely fear what I would do if an abnormal child were born to me. I can't say that John has changed all of that but I can readily say that I love him . . . If by an chance I do have such a child, I feel I will honestly be able to love him as I do John."[1]

Some research workers assess the impact of a group of mentally handicapped children in a "normal" school: "The assessment of the attitudes of the nonhandicapped to the handicapped suggests that the special class children were well accepted by the regular pupils, corroborating evidence coming from a survey by a teacher who asked her pupils what had surprised them most about the special class children. The most frequent response given was that they were surprised to find the retarded children were not dissimilar to themselves and were different from each other. Other students have found that the major result of integration is in breaking down stereotypes."[2]

A principal of an "integrated" school talks about the first three years' experience: "Many parents of normal children have had an opportunity to see that a school for the retarded looks very much like other classrooms. Many prejudices have been broken down and offers of help received."[3]

A senior social worker reports on a weekend shared with colleagues and some mentally handicapped people: "The weekend brought me back to contact, in a sense, with the real world. I was more than encouraged by what I found; I was stimulated and enthused. Apart from enjoying it tremendously, I was both surprised and impressed by the contribution made by the mentally handicapped delegates. I am more inclined to question some conventional suppositions, such as the hopelessness of doing much with long-stay hospital residents. The weekend reinforced the need—so easily forgotten in large-scale organizations—for individualization always. I met a lot of very nice, very varied people." A colleague who had been at the same weekend says: "Most people don't know how to listen. Handicapped people can teach us to listen. They should always contribute."[4]

A mentally handicapped person says: "You don't like to be domineered too often; we're not kids, we're over 21. We're not stupid, we don't like to be domineered. Staff say, 'Don't be cheeky,' they don't like you to speak your mind up. If I didn't speak for myself, I wouldn't be where I am today. I used to be shy, people just trod on your toes. I don't like to be domineered too much. It's not right. People have to have a life of your own."[5]

Mentally handicapped people themselves are one of the most powerful instruments of change we have. They are also the most underused. They, after all, are receivers of service; it is easy to forget that they can be givers too. They would not have drawn our attention at all unless they were in some way unable to cope with the demands of society; it is easy to forget that they too have their perceptions and gifts. They are not, by our definition of their condition, "doers"; it is easy to forget the contribution they can make simply by being who they are. They should be glad of our efforts to make changes which will improve their lot; it is not so easy to take account of their views in our planning. And so, in a world where the change and reform we want to see are often bedevilled by lack of resources, we can ignore the one resource which will never be scarce: the handicapped person himself. And yet to find ways of acknowledging and encouraging his contribution seems to me to be one of the most important challenges facing anyone who is trying to change patterns of care. If we do not, we are in danger of settling for change which could end up as unresponsive to the needs of handicapped people as much of what has gone before.

The handicapped person helps change simply by being there. His presence helps break down the barriers of fear and awkwardness which have grown up between him and the rest of the population in a way that no amount of reasoned explanation of his condition can. The children in the normal school study from Ontario quoted above were mixing with handicapped children and were learning that the mentally retarded are people too and just as individual as they are. This is what they said; what they did is as heartening. The study made a special point of looking for signs of bullying of the retarded children.

"The data is quite striking and clearly shows that far from the special class children being victimized by the nonretarded children, they were actually aggressed against less than the contrast group at the segregated school (where the source of aggression was other handicapped children) and the large majority of aggressive acts at the regular school that did occur were performed by other special class children. Further, the special class children received much more positive attention than the children in the segregated school. It seems that interactions involving only retarded children, though predominantly positive in character, included more unprovoked aggression and less teaching, intervening and comforting/helping than interactions involving nonretarded and retarded children. The nonretarded children were definitely not apathetic, uninvolved bystanders to children in distress, even when the distress or predicament was relatively minor or when the retarded children did not seem appreciative of their efforts."[6]

The principal of another school visited during this study underlines this point, " . . . one of the major benefits of the integration to date, in addition to extensive interaction between retarded and regular students, was the help given by the regular students in the special programme."[7]

These sorts of reaction are not confined to children, although the evidence is perhaps more anecdotal. An authority in Britain, to take one example, was not very long ago having a great deal of trouble setting up a home for handicapped adults in a residential area. The neighbors' objections were along familiar lines—fears of handicapped people themselves, cloaked by fears for the value of their property. Reasonable explanation and reassurance had not been enough. The project seemed doomed to failure. At the final public meeting, where the authority had its last chance to sway opinion, it brought along some of the prospective handicapped residents of the home. The hostility with which the meeting opened turned to embarrassed silence and then to tentative curiosity. The handicapped people were asked what time they went to bed, where they went to work, that they did with their leisure time. Their replies were so normal that opposition collapsed. How can a man sustain the myth of the dangerous retardate about to attack his wife and children if that same man is so evidently interested in watching television and going to the pub?

If we are beginning to accept that handicapped people can often put their own case better than the "experts" can on their behalf, simply by being who they are, we are farther from acknowledging the contribution they can and should be able to make in determining the pattern of services they use. Yet, if we stop to think at all, it is little short of grotesque that we have ignored this contribution for so long, for it is essential if the pattern of services we develop is to be the right one.

This is a point which is slowly being recognized for other groups who need society's help, not least through the determined efforts of "client organizations," the new style of voluntary body which started very much with the parent groups in cerebral palsy and mental handicap. The involvement of parents on behalf of their families has since, in some areas, developed to an involvement of the person most concerned, himself. In Britain, for example, organizations which work on behalf of groups like unsupported mothers and the poor are finding they must take account of groups made up of unsupported mothers and people living on welfare benefits. Their right to express their own feelings about the help they receive and their right to be consulted about the kind of help offered, is slowly being recognized. Social workers on both sides of the Atlantic are acknowledging the value of "client-oriented" studies. As one study of working class reactions to casework puts it: "Clearly, until we have investigated consumer opinion we cannot begin to be sure that social work resources, likely to remain in very short supply for the foreseeable future, are deployed in the most effective way possible, to say nothing of whether they are achieving the goals for which they are designed. Nor shall we have a firm basis for improving services in the future."[8]

Mentally handicapped people, no less than any other consumer, have their contribution to make here. This contribution is relevant even in the most evidently expert areas of therapy. What, for instance, are we to make of a not uncommon way of coping with someone with "behavior disturbance" when we hear this account of what it is like to live with the therapy of the sideroom? "It's horrible, there's nothing to do but sleep, sleep, sleep. It's very cold, you couldn't go to the toilet, there's no pot in there. You get a pot and a mattress, no blankets, no windows, food pushed through the door. Nobody came to talk to me, not even the doctor. Here's your food, eat it, but they won't talk to you." This same young woman was able to criticize another handicapped person who advised locking up a "troublesome" person: "That's not making a fuss of him, it's beating the daylights out of him; you've got to gain his confidence, talk to him."[9] Who is to say that her therapeutic approach is not worth considering? We too easily ignore the often remarkable sensitivity and understanding which people we have labelled as simply "receivers" bring. Very often their insights into the anguishes of others are far more true than our own; so often, after all, they have been there themselves.

What, again, are we to make of some of the current wave of token economies when one woman involved in such a scheme reacts to it with resentment, but even more with bewildered sadness at being treated as an incapable child by the very people who are at the same time telling her she should grow in responsibility for her own life? The way these schemes are administered and explained to those involved should surely be looked at more critically. What constitutes "consent" to these programs? We surely owe it to both the handicapped people and the staff involved to make regular discussion of how they are reacting to them a part of the scheme. Consent here is only meaningful if it is continuing.

A third example: can we really say that we have got the right approach in the environments we provide for "disturbed people" when one who has lived in them can say: "It's very strict, you feel like running away from places like that. You can't stand it after a time, go back home. If you had freedom, you'd stay there. I think probably many would stay there. They wouldn't want to run from places, run away from home."

If staff were able to listen more to handicapped people's perceptions of life in our different residential establishments, the fabric of that life might have to change considerably. The declared aim of our residential services is to encourage as much independence as possible, and this is certainly something that many handicapped people want for themselves. Yet, too often, handicapped delegates to Campaign for the Mentally Handicapped conferences in England have seen their life as not fostering independence at all. They wanted to help around the house, for instance, but they could sometimes be told that this was for the staff specially hired for the purpose. They were often not allowed to make themselves a cup of tea and invite friends to drop in; their participation in preparing meals was on the level of duties rather than of sharing. They would like to have had a say in the way their room was decorated or even help paint it themselves, yet often they were presented with a finished product chosen before they moved in. Some even had their clothes chosen for them by staff; many had little idea how to handle money because the staff kept it for them.

Many delegates felt that it would be better if staff did less for them—especially as they were very aware of how much work the staff had to do. Ideally, staff were seen as housekeepers who would help with the cooking and cleaning and as guides who would enable the handicapped people to cope with the intricacies of everyday life or as friends with whom you could sit down over a cup of tea and chat.

This sort of comment was a reflection of the more fundamental pattern of relationships between handicapped people and their staff. For some, staff were indeed helpful—particularly for those who had known the same staff over many years in a large institution. "The nurses haven't let me down; they've given me great pressure to go my own way, live as I want to keep myself. If people like to put themselves forward, no one knows what can be done till they speak their mind. Nurses help people who want to be helped."

For others, though, staff could be seen as unapproachable. They were people who gave orders. "Do this, do that, sometimes an argument, sometimes you do it, sometimes you don't, then they get cross." "You musn't give the staff cheek. I call them 'sir' for a joke, sometimes, and salute, but you have to be careful. It's like the army, you see, the staff are in charge, that's why they wear uniforms."

Staff could be the people who gave you punishments if you broke the rules. It was not uncommon for men and women of over 30 to be living in situations where being sent to bed or deprived of their week's money was the normal reaction to misdemeanors. Staff could be people you had to keep on the right side of because they could keep you in when you wanted to go out. "All the staff like me because I help them a lot. Then they help me a lot. I ask for an all-day pass and they say yes and I go."

Some of these perceptions apply more to large institutional settings than to the newer forms of residential care in the community. But overall, there was a feeling that staff were people who told you what ought to be done rather than consulting you about your preferences, who were usually too busy to listen to what you had to say or too impatient to put up with your fumbling for the right words. Delegates had a feeling of powerlessness, of being ignored in matters which affected them quite vitally. "When they have conference meetings like this we're having now, it's just the nursing staff and doctors—only what they say. I think that's wrong because I think myself they should let the patients stand up on their own two feet, you know what I mean?"

Sometimes the decisions taken on their behalf were absolutely fundamental ones. To one woman, it seemed that people were moved from the institution which had been their home for many years "like a sack of potatoes," on what seemed to her no more than the say-so of a social worker and with minimal consultation. How many people have any choice at all in those they share a home with—a choice which most of us would find fundamental? It would not be so hard, after all, to ask people their preferences and to organize lengthening visits to the home before the final decision to move in has to be made.

This lack of thought and finally of respect for handicapped people can have truly terrible consequences. One woman recounted how she had decided not to leave the hospital because there was no place in the community home for her boyfriend. The two of them had discussed this and decided to tell the social worker of her decision. But when the day came, everyone was in too much of a hurry and there didn't seem to be the chance. The residential home is many miles from the hospital; the couple can communicate only when someone has time to write a letter for them and they meet even more rarely when the woman is able to get transport to visit the institution.

This sort of situation is not confined to residential settings. One young man was asked by the person responsible for jobfinding if he would like to work in the local abbatoir. The word was mysterious, but he liked animals and the pay was good: he agreed. It was only when he started work that he found out his job involved slaughtering animals. He lasted two weeks. The distress the experience caused him was evident even two years later; he was still a vegetarian. The fact that he had left the job was, of course, a strike against him which, in the prevailing state of the labor market, he could ill afford.

Consultation is easier said than done. But surely the providers and organizers of services have a duty to explain, to demonstrate, to reiterate, to enable trial periods, until "choice" becomes real for the handicapped person whose life is so vitally affected by decisions like this?

The feeling that people in authority have little time to listen and discuss could be perhaps particularly hard in a community home where there are so few staff. Outsiders offered little support. Social workers, it seemed to these delegates, "couldn't be bothered" to come and see them or spend time with them. This was particularly hard when many of the delegates found their homes relatively isolated in their communities with few outside friends.

This failure to take account of the feelings of handicapped people can start further back with the very shape of residential settings in which they find themselves. Delegates spoke very often of the strains of sharing a room, of not being able to turn up your radio when you wanted to, or simply to have an early night undisturbed. The lack of privacy could be intolerable. When one woman felt like crying, she could only wait until the other women who shared her room were asleep. When one man felt sad, he would go and sit on his bed so that no one could see he was crying and then go for a walk round the hospital grounds until his mood improved. Having to live with so many people whom you had not chosen could be a further strain. A small group of six or seven chosen friends seemed ideal. And yet in Britain, official government policy still allows for community homes of up to 25 people and many are not consulted on whether they want to share a room, far less on who they live with.

What is the effect of deciding that this should be the way of life for large numbers of handicapped people? Many delegates to the CMH conferences found themselves in situations where the lack of consultation was painful and difficult to them. Living together is often no easier for handicapped people than for the rest of us. It is possible that we are creating forms of residential care which, by ignoring the views of those who have to live with them, make their progress to fulfillment more difficult and thorny than it need be. The strains of everyday life were often increased by what seemed to these delegates to be authoritarian, unsharing, or simply "too busy" attitudes on the part of staff. It is possible that by failing to listen to handicapped people, staff make their own lives and those of residents harder than they should be.

How are we to change some of the directions of our services by enabling mentally handicapped people to make their own contributions to that change? The first way is fundamental to the patterns that develop. We have seen that the mentally handicapped person, simply by being there, can often help to dispel the barriers of fear and distrust which have grown up around him and that normal children are particularly responsive to the handicapped child, not as a "freak" but as an individual who may happen to need special help. This perception is so central to the success of reform that it is surely vital for us to plan our services so that it has a chance of growing among more and more people. We are at a point where we have to choose whether we are to continue the segregated policies of the past, in however kindly a new community form, or whether we are to start from a commitment to finding ways to make integration work, with special provisions only when we have honestly examined and rejected more integrated alternatives.

This is not simply a question of forging closer links between normal institutions and special ones. It is a question of bringing the handicapped child into the ordinary school campus, of encouraging foster care, of looking, in Britain at least, at ways of integrating handicapped children into our normal provision for the child in care. This last has been done by a large voluntary agency in the Northwest of England for over three years now. Some 10 mentally handicapped children, of whom the oldest is now 11, are living in 6 ordinary children's homes and others have been admitted for short-term care. Some of the children are extremely multiply-handicapped or overactive; none has had to leave the home because of management or other problems.

This pattern of residential care seems more than feasible in the British situation. The normal children in the home, when compared to a similar population in residential homes which do not include handicapped children, have suffered not at all. When the handicapped children are compared to similar children in segregated children's hostels for the mentally handicapped, they show a very small measurable difference in development; but there are measurable indications that they are likely to improve more than the special home children over a long period. They are neither bullied nor bullying. The nonhandicapped children tend to protect and teach them; one has, for instance, taught all the retarded children in his home to ride two-wheeler bicycles.

The nonspecialist child-care staff perceive the handicapped children more and more as they perceive the others. New staff, indeed, have an initial shock when they see how older established colleagues are able to interact with the handicapped children—a shock they soon get over. Overall, the staff are convinced that the handicapped children bring a great deal to the home. They actually find them easier to look after than the others, as their problems tend to be physical rather than those of deprivation. Not one of the homes would return to the segregated pattern.[10]

For adults, we need perhaps to be less concerned about neighborhood reaction than we have in the past. Time and again, it seems, that people will object to the best-reasoned cases for setting up a house in their street for handicapped adults; yet, once they meet those adults, once indeed those adults move in as any other neighbor might, without trumpets and fanfares and explanations, they will accept them well.

We need to examine more optimistically the possibilities of well supervised sheltered lodging schemes, of sharing situations with young single workers. We need to find more imaginative ways of drawing handicapped people from special training centers into sheltered employment within ordinary industrial complexes. We need to think constantly of ways in which people who have been labelled normal can meet people who have been labelled handicapped on common ground. We need a greater faith than our planning often shows that the handicapped person is worth meeting, that he too has his contribution to make.

This is not to say that there will not be problems of integration. Of course there will. But a clear commitment to this pattern of care in future, instead of compromise reforms, would in itself go a long way to draw public support, and the problems which came up would be a lot healthier than the problems of the past with which we are now living.

This is a first step to acknowledging the contribution to change that the mentally handicapped person can make simply by being himself and being there. How are we, at the same time, to find ways to listen to him and acknowledge his contribution to the planning and running of our services?

Clearly, some handicapped people find it easier to articulate their feelings than others—although the Campaign for the Mentally Handicapped conferences have shown that people who may find it quite hard to follow the thread of a conversation and join in can have important contributions to make if we just have the time and patience to listen to them. Anyone who has worked in residential care will know that communication of likes and dislikes is not dependent upon speech. Nevertheless, our patterns of service in the past have ensured that many handicapped people have not had the chance to make their best contribution. They have been denied the variety of experience on which realistic choice must be based. It is clearly quite wrong to ask someone who has lived in a large institution all his adult life whether he now wants to live in the community and act on his reply. How does he know? How can he hypothesize? One of the most important duties of any service is surely to provide the range of experience and the means of evaluating that experience on which future choice will be made. This remembered, we can begin to explore ways in which the handicapped person can be enabled to contribute to the services with which he must live.

Campaign for the Mentally Handicapped held the first British conference for mentally handicapped people in 1972, with delegates drawn from all over the country—from hospitals, local community homes, and their own family homes. Its second weekend, the following year, was set up to bring together consumers and providers of service from one London borough, some of whom actually lived and worked in the area and others of whom were still in the hospitals which serve it but who were "on the list" for moving into the community. The aim here was to enable community workers and residents to meet each other, for both to meet people who might in future be more closely linked to them than they had been in the past, and to try to establish some feeling for the way in which services should be developing in this one area. Since then CMH has held two weekend workshops where providers and consumers of services were invited to live together, discuss, and share leisure activities but, most of all, simply to be together not as staff and handicapped clients but as people together exploring ways of appreciating each other's company and sharing experiences.

Clearly, such conferences are only the beginning of the participation of handicapped people in the services we provide for them. Since the first two reports of the CMH conferences were published, there has been a fair amount of interest in this sort of activity from different groups and areas of North America. There is perhaps a danger at the moment of a certain "tokenism" here.

To hold a conference for handicapped people is in danger of becoming a proof that we care. In fact, if it is not done with a view to the continued and patient involvement of the handicapped people in matters which affect them vitally, this can become simply a form of self-gratification for the organizers. Anyone who has been at the last sessions of CMH conferences and appreciated how much work is behind delegates' wondering what is going to happen now, must be aware that holding the event at all has to bring a lasting commitment to finding ways of making sure that something does. CMH, as a small voluntary body, is very aware of its own incapacities in this area. It is also, however, aware that no outside body can do more than begin to enable this sort of change. The essential first step is change in the relationship between staff and handicapped residents.

This is not going to happen overnight. Staff are very often frightened of the challenge that ideas of participation represent. They are, after all, a direct questioning of some of the common assumptions of residential, or indeed any other, care. One study of English homes for severely physically handicapped residents brings out many of the same elements in relationships with staff as CMH's conferences have done. The handicapped people in this study find themselves caught in a caring system which in very fundamental ways must take their own "uselessness" and the staff's "humanitarianism" as starting points. So any complaint by residents becomes ingratitude, an offense against the humanitarian and kindly basis of the home. Any move to greater independence can be seen as a threat. "One suspects that staff who reject aids, whether on the ground of expense or on the ground that the inmates are too helpless to manage them, are really expressing an inability to tolerate a measure of independence in those they look after." The authors go further than this: "Indeed, we postulate that staff attitudes towards the use of electrically operated wheelchairs are perhaps the best single indicator of the prevailing value system." They found a good many staff who did not like electrically powered wheelchairs.[11]

So it is not perhaps surprising how caring staff in one British institution for retarded people reacted to a courageous colleague's report of a survey she had made on what a group of residents thought of the place. They reacted not with a willingness to learn from their criticisms and appreciations, not even with a willingness to listen to the findings, but with a stony refusal to accept that the whole exercise was more than a psychologist's stunt.

So it is perhaps not surprising that a senior social worker left one of CMH's participation workshops after the first session, which had been designed to help people come out from behind their roles and to break down assumptions about who was "in charge," because she found the whole experience too painful. It is not surprising that staff will react to discussions about participation or even sessions where they have discussed very openly with handicapped people by saying, "Yes, but my residents are a lot more handicapped than this." It is not surprising either that residents who have opened during a brief weekend, from being people who simply agreed with almost anything said to them to being people with very definite views of their own, find it hard to go back to their residential situation and be so open.

Nevertheless, staff and residents who have come together to the CMH conferences have been able to go away with greater understanding of each other as people. For the residents in particular, this may help in their efforts to be heard in the future. "When you're in hospital and you talk to the doctor or someone like that you get a bit nervous, you know, of really saying what you do want. It's all right nov, because the nurse is here. He can say that I'm not frightened to speak up for what I do want," one said. There is security in numbers; one group of residents from the same establishment have gone back from one of these conferences and, to the delight of the staff there, have insisted on weekly meetings for both staff and residents to discuss the way the place is going and iron out difficulties. CMH itself is now working on the possibility of using video tapes made at the last weekend as the basis for staff training sessions in the future.

These are beginnings but they are only that. We are back to the central point: no outsider can come in and tell any establishment how it is to enable a truly sharing situation. That means each group of staff and residents committing themselves to a great deal of patient work and that, in turn, depends on active encouragement and belief that this is right from the people responsible for services. This is not something which can be achieved overnight or without some growing pains, for both staff and handicapped people. (A discussion of the particular contribution which l'Arche communities are trying to make to this complex question of sharing relationships appears in another part of this book.)

We are not talking here about grand democratic designs. We are talking about people living and working together. We are talking about people sharing both responsibility and credit for the way their home looks and the way the food tastes and the warmth of the welcome offered to visitors. And we must recognize that although someone may be contributing on only very simple levels, his contribution is nonetheless essential to the whole.

We may also be talking about "formal" weekly meetings between staff and residents to discuss the way things are going, what they will do with extra money or how they will spend leisure time. It certainly seems true that in some situations this sort of structure seems helpful to both staff and residents. But at the same time, we perhaps need to be careful that those formal situations do not detract us from basics. Young people in Sweden, in a pioneering conference, demanded discussion about parliamentary procedure and Trade Union membership—a mark perhaps of the success of normalization in that country.[12] But if that sort of demand is to be replicated elsewhere, we must be sure that we do not forget that democracy and fraternity must also be found in residential settings. In the same way, even group meetings in these settings may be less than fully relevant if we do not remember at the same time the need for less demonstrable evidences of mutual respect and sharing. There is little sense, and even a painful irony, in including mentally retarded people on Human Rights Committees if at the end of the meeting they must return to a ward where there is little respect for and sensitivity to the rights and needs of each individual.

If we are only beginning to find ways of ensuring that handicapped people can make their best contribution to change within their residential settings, then we are further yet from finding ways of bringing them to the planning of services. Many of the delegates who held planning jobs went away from one of the CMH workshops convinced that handicapped people did have a contribution to make here. "I have always felt that the mentally handicapped have an invaluable contribution to make and that their views can be a gauge of the effectiveness of services. The weekend encouraged me in this respect. We must try to involve the mentally handicapped in areas that are important to them. My conclusion from the weekend is that these efforts are likely to be very fruitful. Since the weekend, I have realized that most people, including myself, have been making the assumption that handicapped people had no capacity or impulse to choose or decide for themselves. However, right decisions and good plans involve intense work and it is necessary to be aware of others' needs. The less handicapped must take responsibility for this in relation to the more handicapped."[13]

For these delegates, then, ideas of drawing handicapped people into the planning process are not pie-in-the-sky. A mock planning session for a club for handicapped people, which involved professional planners, shop-floor staff, and handicapped delegates, showed clearly enough that given a practical project, it is often the handicapped people who are more realistic in their approach to limited resources than the staff who want to see something rather grand as a result of their efforts. And yet the weekend showed too that planners like to talk in abstracts a great deal of the time while handicapped people talk in practical, personal, and often emotional terms. This can be embarrassing for the planners; it is they, rather than the handicapped people, who need preparation for meetings of this sort, to enable them to revise their own notions of what is interesting and relevant, of what is a suitable topic for discussion. We are back to enabling staff to accept the contribution of the handicapped person, particularly hard, perhaps, when those staff are removed to the abstract heights of planning from a world of day-to-day relationships.

There are also considerable administrative barriers to participation at this level. Some two years ago, the English Department of Health launched, after much planning and discussion, a scheme to build hospital units up and down the land for the people officially defined as the "young chronic sick." The prospective customers of these units, who are indeed very severely physically disabled but not generally any more "sick" than the rest of us, were not consulted in advance. It was only thanks to a voluntary organization that there was any meeting between customers and planners at all. This brought, not surprisingly, moments of great embarrassment and unease for the planners confronted by indignant consumers putting an excellently researched case for more independent ways of living. If this sort of situation can arise for people who are evidently capable of giving their views on how they want to live and the help they need to achieve their greatest independence, how much more are our officials going to be embarrassed by the realization that mentally handicapped people too have views? The machinery for consultation is not there, even if the inclination for listening grows further down the administrative ladder. We should be working now to create it.

One of CMH's group leaders summed up the first participation workshop like this: "One has to start with attitudes, not programmes, because in this life all programmes stem from personal attitudes and beliefs. That which is possible is that which I believe in. If I don't believe, or if what is proposed goes against my beliefs, I will find a thousand and one ways to drag my feet. There are a large enough number of people who believe that the mentally handicapped are human beings and these people can be given moral support and know-how in the art or practice of participation. However, there are a large group of people, many highly placed, who do not believe that the mentally handicapped are human in the real sense of that word. These people must be confronted. Existing or planning services for the mentally handicapped must recognize them, show disapproval of their attitudes and try to alter them; otherwise, the services will end up no better than any service that has gone before."[14]

This is the challenge. Mentally handicapped people are one of the most powerful instruments of change we have. They are still the most underused. We need, first of all, to see their faces, not just as occasional visitors into our world, but as members of it. We need to learn to listen to what they have to say, and to act, together with them, on their perceptions and our own. If we do not, what chance is there that our changing patterns of service will be any more than the old ones dressed up, not to meet the needs and proper aspirations of handicapped people themselves, but to satisfy our own ideas of what is good for them?

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25. L'Arche

Ann Shearer

L'Arche started in 1964 as a small house in Trosly, a village in Northern France. Ten years later, it is an international federation of communities where mentally handicapped and "normal" people live and work together. There are almost 50 homes in France, Britain, Belgium and Denmark, in the United States and Canada, in India, and in Africa. It is, in very many ways, the most challenging and exciting development in residential care for the mentally retarded of the last decade.

For a start, its growth rate is remarkable by any standards. At the moment, and there is no sign of this stopping, it can not only attract enough workers to sustain its existing houses and open new ones every year, but in several houses is actually turning would-be helpers away. And its ratio of assistants to handicapped people is almost one-to-one at Trosly and in other homes not very much less. At a time when almost every Western country is coming to realize that the greatest block to radical reform of its residential care services is the sheer and often frightening lack of staff, it is clearly worth looking hard at what l'Arche is about.

Its growth is perhaps the more remarkable because at first, at any rate, it started almost by accident. When Jean Vanier gave up his job as a philosophy lecturer in Toronto to move into that first small house with a couple of men from a nearby psychiatric hospital, or even when he was asked to take over an institution for 30 handicapped men in the same village a few months later, his sights were hardly on an international community. His concern was to create "a home of mercy where the rejects of society could find refuge and where they would be welcomed with kindness and compassion." The very name of the community—the Ark—shows the original perception: an operation which would rescue people from the mounting tides of society's indifference. As l'Arche has grown, its rescue operation has become something a lot more creative and dynamic than the first definition implies. But the growth retains something of the early haphazardness, as workers turn up who launch their own communities, as existing homes apply to join the federation. This is why it is hard to pin l'Arche down in conventional organization and management terms. At the same time, it is this quality of organic growth which is one of its strengths.

Communities Vary Worldwide

L'Arche has found no organizational recipe. Each of its communities takes its character very much from the people who start it and come to live there and from the cultural conditions in which it finds itself. The original house at Trosly is now one of some 14 scattered throughout this village and others nearby and in Compiegne, the nearest sizeable town. The community has nearly 300 members, living in groups of 12 or so in ordinary local housing and working in the community's own workshops and grounds. The centers at Ambleteuse, on the North Coast, and Cognac, in the South of France, each have about 100 members and follow much the same pattern. In Paris, by contrast, the community is about 10 strong, made up of students and people working in ordinary employment or sheltered workshops. Daybreak, the first North American community, now has about 50 members who live on a large site in a well-to-do suburb of Toronto, some working on its farm and in its bakery, others in a nearby sheltered workshop. In Ottawa, Alleluia House has about 20 members, working locally in open or sheltered employment. Asha Niketan in Bangalore is about the same size. In Calcutta, 10 people live almost on a platform of the city's busiest railway station with their own industrial subcontract workshop.

Methods of financing differ too. In most of Europe and North America, capital development is financed chiefly by government grants and loans; there are per diem grants for each handicapped person. But in Victoria, British Columbia, and in Copenhagen, for instance, each member of the community contributes to the expense of the house, and this financial independence is a pattern which is growing. In India, l'Arche money is backed by CIDA, the Canadian Government's International Aid organization.

L'Arche has not found a formula, either, for the kind of handicapped person it accepts into its communities. It is certainly true that those who come to live in l'Arche houses must be able to sustain living in a group in a setting where there are no locked doors and almost total freedom. It is true too that it gives priority to those for whom a traditional institution is the only possible alternative and that no one under the age of 18 is eligible to apply. Selection is carefully made through a series of lengthening trial visits, which can be stopped at any time without either the handicapped person or the community feeling they have failed.

Clearly, the person who is extremely and constantly destructive of himself or others cannot be welcomed into a l'Arche home. Because these are working communities and because of the sort of staff that l'Arche has, the very sick or virtually bedridden person cannot be welcomed either. L'Arche does not pretend to have found the structures for accepting those people who all over the Western world present the greatest challenge to creative residential care.

Nevertheless, the people who join l'Arche communities have a wide range of handicaps. There are those who, by IQ measurement, are little short of brilliant but whose emotional problems are so considerable that they find it impossible to sustain a working life outside of a sheltered environment and often find it difficult to sustain one within it. There are those who, again by IQ measurement, are very severely handicapped but who are very good gardeners. There are those who cannot talk and those who will treat you to a dissertation on the world economic crisis. There are those who, in the traditional way of measuring ability, need help to feed, wash, and dress themselves, and there are those whose sartorial concerns put a lot of the assistants to shame. As anyone concerned with mental handicap will admit, if he is being honest, they are the sort of cross-section of people you will find anywhere that society decides to reject, people not capable of functioning at that level which it considers indispensable to living in the "normal" community.

The people who make up the assistants form a group which is only slightly more cohesive. There are a great many who are young and want to take a year or so before continuing their studies. There are almost as many who have completed their studies and want to take time to consider where to go next. There are rather fewer who have already worked successfully in the world and decided to look for another way of life. There are those with professional qualifications in disciplines like psychology and sociology who feel drawn to what l'Arche has to offer. There are people who come for a year and stay a month and people who come for a month and stay for two years and upwards. What unites them perhaps, at one level, is a lack of concern for contracts and salaries, for although some need money, most are happy to settle for board, lodging, and pocket money.

A Common Belief

What unites them more profoundly and what keeps the very different l'Arche communities together as an entity that is identifiable at all is a belief. Its inspiration is certainly a Christian one. "The first aim of l'Arche," says the Federation's Charter, "is to create communities inspired by the Beatitudes and the Spirit of the Gospel."[1] Most of the assistants who come to l'Arche and particularly those who make a long-term commitment to one of its communities will be very deeply inspired and sustained by their own faith and attracted to l'Arche because its way of life seems to them to be putting that faith into action.

And yet l'Arche also attracts assistants who have no formal Christian beliefs, although even the staunchest nonbeliever must occasionally wonder at the length of the arm of coincidence which brings money at the moment it is most needed and seems least likely to turn up, at the chance meetings which lead to new communities; luck doesn't usually run in 10-year batches. It is attracting growing support in India from Hindus whose own faith brings an approach to the place of the individual in the cosmos that is very different from the traditional Western one. It would be too glib altogether to docket l'Arche as a "Christian" foundation and then to dismiss it as irrelevant to nonbelievers. If l'Arche relied entirely on a traditional Christian calling, it would be, if not shrinking, at least growing very slowly in this secular age as the number of practicing Christians falls and the number of religious living in traditional Catholic communities is lower than at any time in the church's history.[2]

And yet community is what l'Arche is about. It is not an organization which believes in offering mentally handicapped people a form of care, however kindly. It is an organization which believes that we must go further than that, that we must try in whatever way we can to break down the barriers of stereotyping and labelling which put us on the career ladder of residential care and them at the bottom of that ladder as those who make our rise possible. It believes in sharing the details of everyday life with as much respect as we can muster for those who have been defined inadequate just as it believes in sharing work and leisure and joy and suffering. This is its challenge.

The challenge would be frankly impossible if l'Arche took any of the traditional views of mentally handicapped people. "We believe," says the Charter, "that each person, whether handicapped or not, has a unique and mysterious value. The handicapped person is a complete human being and as such he has the rights of every man: the right to life, to care, to education, and to work. We also believe that a man who has been wounded in his capacity for autonomy and in his mind is capable of great love which can be called forth by the Spirit of God. We believe that God loves him in a special way because of his very weakness. Because of his handicap and because he feels rejected, a wounded person may shock or repel. But given an atmosphere of security where his latent capacities can develop, he can also radiate simplicity, welcome, joy, and peace."

It is this belief in the handicapped person and in his value which runs right through the life of its communities and holds them together and it is this belief which can attract and hold assistants of fairly different persuasions. The particular qualities of handicapped people are a central theme of Jean Vanier's. "Handicapped people, particularly those who are less able, are frequently endowed with qualities of heart which serve to remind so-called normal people that their own hearts are closed. Their simplicity frequently serves to reveal our own duplicity, untruthfulness, and hypocrisy. Their acceptance of their own situation and their humility frequently reveals our pride and our refusal to accept others as they are. So often so-called normal people have interior barriers that prevent them from relating with others in a simple way. All of us have deep needs to love and to be loved. All of us are in the conflict of our own fear of death and of our own poverty. We so quickly pretend that we are more clever, more intelligent, and more powerful than we actually are. So often we flee reality by throwing ourselves into activity, culture, the struggle for power and prestige. We lose contact with our deep inner selves. Handicapped people do not always have these barriers. In their poverty, they are more simple and loving and thus they reveal to us the poverty of our riches." This is a view of handicapped people very far from the "basket cases," "retardates," "lowgrades," "highgrades," "Mongoloids," and so on that we still so often hear, and hear not among members of that world of public indifference against which we are struggling but among members of our own caring professions who know handicapped people well.

This view of the handicapped person, not as a liability on the balance sheet of care but as a giver, goes further. "The tragedy of humanity is not primarily the lack of development of people or even poverty. It is the oppression, the despisal, and the rejection of those who are weak and in want. It is the horrible and disastrous inequality of wealth and opportunity and lack of sharing. The tragedy of man is his hardness of heart which makes individuals and nations endowed with the riches of this world despise and consider as inferior those who are poor and handicapped. They not only refuse to help them, they tend also to reject and exploit them . . . The tragedy of our world today is that man is still afraid of man. Far from seeing other individuals and peoples as collaborators in the mystery of universal human growth, we see them as enemies of our own growth and development . . . If we listen to (the weak and handicapped) then we, the so-called normal and valid people, will be healed of our unconscious egoisms, our hardness of heart, our search for power, and our dissipating leisure. We will discover that these (people) can become the inspiration for all men. We will realize more fully that men are not machines or objects to be used, exploited, tyrannized, and manipulated by law and by organizations but that each one is beautiful and precious, that each one in his uniqueness is like a flower which should find its place in the garden of humanity for the fulfillment and beauty of all mankind. If each one of us who hold responsible places in society pays attention to the heart beats of the smallest, the weakest, and the companionless, then gradually we will make of our countries not lands of competition, which favor the strong and powerful, but lands of justice, peace, and fraternity where all men unite and cooperate for the good of every man."[3]

Respect for the handicapped person, then, is not only essential to his growth and something which brings enormous gains to the rest of us in our relationships with them and anyone else, but essential for the very survival of the world. While this is as true of any rejected group as it is of the mentally handicapped, they carry perhaps special symbolism. They, after all, are the archetypically useless members of society. Unlike the aged, they can claim no consideration for the contribution they have made to society; unlike the problem child, our efforts to help them will never turn them into economically productive cogs in our societal wheels.

All this may seem rather elevated and remote from the everyday realities of residential care. But it is often this view of the handicapped person, not as a liability in the world but as its safeguard, which attracts to l'Arche communities young people who are looking for alternatives to our materialistic and achievement-oriented societies. It is even more often this consciousness of the handicapped person as someone with special gifts of openness, honesty, and sheer capacity to enjoy living that keeps them there. "Really you come here thinking you want to serve, help out where you can, but you get more out of it than you can possibly give." "They don't look for anything but the essentials. When they can't verbalize, when they can't speak very well, they don't know enough to have the damn stupid hang-ups we've got. It's just real simple." "There's no pretense to them at all. They're real people. They are more real than so many people I know, who are supposed to have everything." These comments from workers at Trosly are fairly typical attempts to put into words why they are living with the handicapped people.[4]

This is not sentimentality. Wolf Wolfensberger, ever on the lookout for distorted perceptions, went to Daybreak in Toronto to sniff out signs that the handicapped people were being seen as holy innocents. "I found no such idealized distortion among the workers of l'Arche, who showed their awareness of the humanity and human weaknesses as well as the human strengths of the retarded." What he did find was an atmosphere where the spiritual life helped to create an atmosphere "in which persons who otherwise might present major problems to one another and/or society live together in tolerance, love, and charity toward each other."[5]

People, in fact, are people, each with their special gifts, and l'Arche communities are places which try to encourage the development of these gifts and the growth of each individual in an atmosphere of mutual respect and understanding. This is perhaps a particularly important therapeutic base for handicapped people, who are less equipped to shrug off lack of that respect and understanding than the rest of us. As Steve Newroth, Director of Daybreak, puts it: "From childhood, nearly all mentally retarded people have been wounded, not only organically but also by the pitying, fearful or indifferent looks of others which devalue and inferiorize them, sapping them of all self-confidence. They need to find true friends who will help them recover their own confidence and self-esteem. A community of deep acceptance can give the handicapped the dignity of being someone with whom others wish to live and share their lives. It can give them a sense of being respected and valued rather than being the objects of pity, fear, and rejection."[6]

What happens in a l'Arche community is not dramatic in any other terms. There are no new drugs or applications of group therapy, although people do sometimes take drugs and have either individual or group sessions with a psychiatrist. There are no new conditioning techniques which can be measured in graphs on the wall, although the conditioning of people to believe they are worth something is clearly at the basis of it all. To say that people in l'Arche communities get up, go to work, prepare meals, go to the cinema, wash the dishes, and fill their days with the thousand and one small things that make up normal life sounds almost disappointing. But it is precisely the willingness to resist doing something for them that is l'Arche's therapeutic strength.

Joyful Places

Visitors to any l'Arche community are usually struck first and foremost not by the quality of the soft furnishings or by the number of lavatories (for indeed the environmental school of thought would find little to write up in the very ordinary housing of l'Arche) but by the sheer friendliness, openness, and freedom of the handicapped people and the quality of their relationships with each other and with the assistants. Life is very noisy, very bustling, and, at best, very joyful.

Bill Clarke, a Jesuit who has spent some years in different l'Arche communities tells a nice story about a couple of men from one of them who were drawing pictures in wet sand on a beach. "'Draw joy,' one said to the other. Claude took a look around him at the wide beach that stretched out in both directions as far as the eye could see, then turned to Jean-Pierre and said with a huge smile but in all seriousness, 'There's not enough room.'"[7]

The sheer joy that l'Arche can generate was one of the things that most struck Wolfensberger in his contacts with Daybreak. He cites the Friday night open house where neighbors and friends drop in to drink coffee, chat, sing, and dance. The same quality is part of any l'Arche feast and there are plenty of those, from birthdays to the great Christian feasts, to welcoming people back from trips out of the community. It can creep up on a meal which will suddenly explode into an orgy of bread-throwing, table-banging, and musical improvisation. It is the quality which had the Archbishop of Canterbury ringing a bell in the greatest and most solemn cathedral in Britain on the greatest and most solemn feast day in the Christian year, but more often it illuminates quite ordinary moments in a way which sounds a lot less good and even silly in retrospect. These are occasions which can lead Wolfensberger to say, "I can scarcely begin to define what I mean by joy in the lives of the retarded because one has to experience this phenomenon to understand it." There are occasions when, as Bill Clarke pointed out, followers of Eric Berne will see that the Child of the nonhandicapped person has responded to the very much more evident Child of the handicapped one;[8] moments which Wolfensberger sees as some of the "very few social occasions in the community at which adults can experience joyful, vigorous group interaction and relaxation in utter innocence." They are the sort of occasions that can make a nurse who brought a group from an institution for the mentally retarded to a very ordinary party, by l'Arche standards, burst into tears because she had never in all her long years at the hospital met such warmth and happiness in the company of the handicapped people. They are the occasions that make a hard-bitten journalist wonder why he felt so high when all he'd had to drink was orange juice. They are, in fact, those very precious moments when a group of people are so overwhelmed with delight in each other's presence that nothing social convention can say will prevent them from expressing it.

Life in a l'Arche community is not, of course, one long custard pie joke any more than it is one long experience of spiritual unity. It would be no service either to l'Arche or to residential care to pretend that it was. It is extremely demanding in terms of sheer physical presence. There are no terms and conditions of service which guarantee time off, and most assistants are financially dependent on the community even for the food they eat. It is even more demanding in emotional terms. "If community can," Jean Vanier says, "in its first months be exhilarating and enriching, it can, as the months and years go by, become difficult and sometimes even intolerable. It is easy to slide into indifference, into routine, and more-or-less egotistical habits. It is not easy to live day after day with people who are at first sight unsympathetic, to be constantly receptive to the other, to reach beyond one's personal interests and need for individual comfort; it is hard not to fall into cowardice or resignation . . . These nine years at l'Arche have shown me that communal life is something rough and difficult. Its dailiness is tiring. The assistants, like the handicapped people, have a constant need for support in their communal journey. They must learn to overcome their apathy, their antagonisms, their aggressions, tensions, and fatigue. They must discover in these aggressions and even in the tensions a new evolution for the community towards greater unity. They must struggle the whole time against all the instincts of egoism, dominance, and fear that are engraved in their own hearts and those of other people."[9]

Life in a l'Arche community can, for a start, be very boring. For myself and for others who have been used to a fairly intensive thinking life with an intellectually measurable end product, the sheer dailiness of moving from house to workshop, workshop to house, can be the most sapping aspect of all in a situation which demands every ounce of emotional energy you can muster. It is not easy to live with people whose past has left such easily opened scars of anguish and whose very suffering opens scars in you that you thought were healed. It is not easy to remain open to someone who is himself closed and withdrawn. It is occasionally frightening to be confronted by verbal or physical aggression. It is very often more frightening to be confronted by one's own absolute impotence in the face of another's anguish, by one's own inadequacies, fears, and self-defenses.

These are all elements in any residential care but what is perhaps different about l'Arche is that they are nearer the surface. Because life is there to be shared, because assistants are not there as experts who can put a professional distance between themselves and the cases they are dealing with, the suffering will be more acute. At the same time, this is perhaps what makes it bearable. It is admitted and at best is worked through in a way that leads to growth. Assistants in l'Arche communities are not expected to be always strong and competent; they are just expected to accept that strong and competent is often precisely what they are not.

Life in a l'Arche community, then, is made up of joy and suffering and sheer dailiness and, if the first two are intensified, then the third must be recognizable to anyone with any experience of residential care. It is perhaps time to ask the essential question: Does it, in fact, offer handicapped people a greater chance of growth than other residential settings?

The view of handicapped people which underlies what l'Arche is trying to do, the relationships it enables between helpers and helped, must make this growth possible. There cannot be many residential establishments which offer such freedom to handicapped people in conditions of so much respect and love. The intensities of joy, and indeed the admission of suffering, would not be possible in many existing residential settings; the quality of emotional life is quite unusually high. So a man who, when he first arrived after years of almost total seclusion because his family was ashamed and frightened of his epilepsy, would not go out of the house, this year went on holiday abroad. So another, whose own fear used to be so great that the slightest gesture of violence would drive him literally berserk, can now master himself enough not only to leave a room when he feels a panic coming on but to discuss his feelings. There are countless stories of this kind, just as there are countless stories of men who came to l'Arche labelled as useless and not surprisingly behaving that way, who now hold down good jobs in their community or even in open industry.

It is reasonably certain that this growth of confidence which is so evident at l'Arche would not be possible or, at any rate, would often be a great deal slower in other residential settings. It is absolutely certain that few offer such a good and full emotional life to their inhabitants. Wolfensberger came away from Daybreak convinced that we have to learn more about "interacting with the retarded on a more equal level." He cites an encounter with a member of staff of another establishment who was wearing a white coat because it was getting harder and harder to tell staff and patients apart, to show just how far our typical residential establishments are from this.

This is not to say that l'Arche communities have achieved a complete equality of regard between assistant and assisted. Each individual will have his own personal blocks to this. One generalized danger that appears perhaps more evident to a non-Christian than to a Christian is what you would call "other cheekism." This is an interpretation of the Christian virtues of self-sacrifice and self-forgetfulness that leads finally not to a repression of selfishness but to a repression of self. It is an interpretation which can mean that the handicapped person becomes rather lost because it is hard for him to find the limits of acceptable behavior in his relationship with an individual. He finds himself in a situation of testing where the response is a turning of the other cheek which must surely both confuse him and reinforce his own feelings of worthlessness. "I lose my temper, the assistant doesn't." The spontaneous honesty of the handicapped person is being met by a kind of deceit, a repression of true feelings for the sake of an ideal of behavior represented, after all, not by man but by God.

There are other, more obvious, blocks to equality between assistant and assisted. The handicapped person is placed in a l'Arche community and his only way out is very often the institution from which he came. The assistant has chosen to come and usually has a vastly more attractive range of outside possibilities open to him when he wants to leave. For many of the handicapped people, marriage is a very remote possibility. The assistants have as conscious a choice here as any other normal person. These are very real barriers to equality and they are ones of which many of the handicapped people are painfully aware.

For many, the only compensation to these will be in the quality of his life in the community. Here again, l'Arche seems to offer a far richer experience than typical establishments. There is almost total physical freedom, particularly in the more rural communities. There is a very real effort to provide work within the community that can offer a range of experience and real choice to the handicapped people. At the moment, apart from industrial subcontract work, maintenance and gardening, l'Arche communities run potteries, mosaic and woodwork shops, a bakery, a commerical chicken concern, and a vineyard. There are weekend visits between communities and all the usual range of cinema-going, bowling, and so on.

At the same time, for those who are drawn to it, there is the opportunity for a spiritual life which can be as intense or occasional as they wish to make it. Although many of the handicapped people have no inclination for traditional religious observance, most of them draw some strength from knowing that it is there. Wolfensberger was very struck by the importance of the spiritual life to handicapped people and concluded that we should encourage this far more than we do at present. It is something very central to life in a l'Arche community.

"The great suffering of the handicapped person," Jean Vanier has written, "is consciousness of his handicap, his consciousness that he is different from others and because he is different he is not loved . . . Who is going to help him accept his handicap? He cannot discover the beauty of his being; we can be nice to him occasionally but living 24 hours a day with him is something different. We can accept our handicap because in another part of our being, we are conscious of the positive and so can accept the negative. But if people do not see the positive in us, we go into the world of dreams: delirium, hysteria, or anguish . . . The handicapped person who has not riches or intelligence or strength has more need of the spiritual life than anyone else because this is his unique treasure. This is why in a very special way he needs the certainty of God's love and God's pardon."

Certainly many of the handicapped people draw their greatest strength from their own faith and religious observance. It is also true that people who in the ordinary way of things have few of the normal abilities of self-expression can talk of their faith and pray with a directness and understanding which has an almost prophetic quality. Often, too, these people have a sensitivity to the needs of others—whether these are "helpers" or "helped"—which most assistants feel themselves very far indeed from achieving.

There is one further element that enriches life in a l'Arche community and that is the consciousness of being part of an international movement. There is certainly a strength for the handicapped person in feeling part of a concern which stretches as far as the Ivory Coast and India; in the knowledge that in countries as far off as this there are men like him who in some way are sharing his life. If the international federation is sustained by Jean Vanier's perambulations about the globe and transoceanic telephone calls, it is perhaps sustained as much by the scrappy homemade cards from the handicapped people that wing their way from community to community.

If life within a l'Arche community can offer growth and a variety of experience, what are the chances of leaving it? Certainly there are establishments which could show a very much faster turnover. To an extent, this is a byproduct of l'Arche's view of the world, for an Ark is primarily a place of refuge and only at the end of the story can you jump off onto dry ground; the handicapped people are perhaps in danger of getting caught up in l'Arche's view of what constitutes suitable dry ground. There is, after all, a contradiction in an establishment which on the one hand is trying to create a way of life and live a scale of values which it feels to be truer than those of the society around it and which on the other hand is encouraging its handicapped members to go out and join that world.

There is a further danger which Wolfensberger picked up. "One thing that bothers me," he says, "is the thought that once a person has realized what he can learn and gain by the presence of the retarded in his life, he may come to need the retarded more than is healthy. When one needs retarded persons in order to be inspired, to be desophisticated, or to feel that one is rendering a worthwhile service, then one will be tempted to keep the retarded in their state of retardation, much like society needs the poor to keep those who are affluent in their state of affluence. Thus, when one needs a retarded person because his deviant behavior meets our needs, there could develop a deeply unconscious but terrible fear that if the retarded person should become less deviant, more valued by the mainstream of society, and more adaptive, he would no longer need us and where would that leave us?"

It is a point which Bill Clarke brings out from his discussions with one of l'Arche's psychiatrists. "To bring a man to l'Arche is to break through the barriers of rejection and constraint that have confined him and to give him a new freedom to be himself. But can the assistants continue respecting the uniqueness and mystery of this person to the point of allowing him to continue developing according to his own uniqueness and inner needs? Can they allow him to continue changing to be free enough to surprise them, and even to change in ways that may make him ever more different than themselves and perhaps to the point of no longer needing their assistance?"[10]

This is clearly a pretty important question and it is much discussed in l'Arche communities. Certainly there are some stock figures on the l'Arche scene who, just because they are very loving and humorous people, are caught in a sort of stereotype of themselves by the delighted expectations of both assistants and visitors. To pick up Eric Berne again, there is often at l'Arche a kind of aspiration to a lifetime of Child-Child relationships which is both simply the obverse side of the positive quality of accepting people where they are and sharing with them there and, more dangerously, a flight from the realities of Adult-Adult relationships which has echoes in some of the l'Arche flights from the normal world.

This is not to underestimate the very real questions with which l'Arche, just as any organization concerned with helping mentally handicapped people to attain as full as life as possible, must grapple. In practical terms, l'Arche has made its own compromise which may well turn out to be more true and enabling for handicapped people than many of the more hardline normalization and integration programs which are now in operation.

While the first communities were deliberately set in the country, physically apart from the industrial society whose demands to such an extent create handicap, the newer homes are more often right in cities and share their lives. L'Arche is also developing its own paths to greater independence. Daybreak has recently acquired a house in the heart of Toronto for assistants and handicapped people who work in the city. Four men who have all spent some time at Trosly are now living quite independent lives in their own apartment in Compiegne, where they are responsible for the rent, the household budget, and the entire running of the apartment. Their links with the community are ones of informal support and friendship. The apartment was not the result of a decision that this was what ought to be done so much as a response to what seemed to be a need. It is this organic growth and widening of l'Arche's patterns which is perhaps important.

The turnover in l'Arche communities, among the handicapped people, at least, is still not great, but what can be said is that it is steady, partly at least because no one is ever pushed before he himself declares that he is ready to go. There is very seldom a situation where a handicapped person fails in more independent living and has to return to the community. It is a way of going about things which is perhaps more ethical than the parcelling up and moving on of people which more rigid dogmas can bring.

Clearly, l'Arche is no more perfect than any other human institution. Some if its strengths are particular to its circumstances, and some of its problems will be familiar to any organization trying to provide good residential care. Nevertheless, it has one contribution to make which is relevant to residential care wherever it is, whoever finances it, and in whatever size of establishment. It is relevant, as l'Arche itself is showing, in cultures as different as the Ivory Coast, India, and Inverness. This is its understanding of what anthropologists call the "gift relationship" and it is this understanding which makes it the most significant contribution to caring for mentally handicapped people today.

The "Gift Relationship"

Richard Titmuss, one of the architects of British post-war social policy, in his last book examined the different systems of blood donation and selling, chiefly in Britain and the United States. He found that the largely commercial systems of the second compared badly with the British system of voluntary donation in practical as well as ethical terms. Quite pragmatically, commercial blood is much more dangerous than donated blood. In one American study of commercial blood, 3.6 percent of patients later contacted serum hepatitis; this would indicate something like 75,000 cases nationally a year and some 10,000 deaths. In every study made in the United States, commercial blood has been shown to be more dangerous to the recipient than donated blood. In Britain, by contrast, the highest incidence of hepatitis recorded has been 1 percent and the most recent study showed a 0 percent rate.

Pragmatically again, the commercial blood system is between 5 to 15 times more expensive in terms of administration than the voluntary donation system. It is also wasteful; between a million and a million and a half units were wasted in 1968 in the United States, when the wastage in Britain was minimal.

From his examination of donor motives in Britain and the way the market works in America and elsewhere, Titmuss argues an ethical indictment of the second which goes far beyond literal "bad blood" to the pollution of society itself. A commercial blood system, he says, represses the expression of altruism and erodes the sense of community. It limits both personal and professional freedom. "If it is accepted that man has a social and biological need to help, then to deny him opportunities to express this need is to

deny him the freedom to enter into gift relationships."*

*It is of interest to note that the blood services throughout the United States are now changing to an all-volunteer system. (Ed.)

The gift relationships which are an important part of primitive societies do not, Titmuss concludes, become less important as our societies become more scientifically and technically complex. They are at least as important as they ever were. The protection and encouragement of man's right to give should be one of the main concerns of our social policy

If it is true that man does indeed have a social and biological need to help, and this seems to me to be inarguable, then Titmuss's analysis of this one small area of social policy must be of tremendous and urgent importance to our understanding of the whole. It is not simply a matter of looking at gift relationships, or their lack, in our residential care for the mentally retarded. It is a matter of looking at the ways in which our increasingly professional and public caring systems either encourage or discourage these relationships between recipient, donor, and the community as a whole, in every area where our societies have taken it upon themselves to help. As we look at the many ways in which people pay the professionals to take over caring through charitable gifts, taxation, and so on, we must wonder as we examine the results whether the ways these systems are developing are the right ones; whether in our searches for systems which bring help to all the people who need it rather than simply to a few, we are not losing sight of the gift relationship between individuals which is a very necessary cement to our arrangements.

This is not to argue for a return to the haphazard arrangements of individual charitable endeavors as the basis of our public systems of care. As Titmuss emphasizes, the gift of blood is characterized precisely by its quality of anonymity, for donors do not give to their friends but simply into a pool. Even less is it to argue for a return to a system of larger-scale private enterprises as the basis of our caring system. The donation of blood in Britain works precisely because it is part of one of the most advanced systems of public welfare in the world. It is a question rather of finding ways to protect the right to give within caring systems which are bound, and rightly, to become more and more professionally and organizationally complex.

To take just one example, the Scandinavian systems of care for mentally retarded people have been the envy of the world. Their quality in terms of sheer physical plant was in their time a revelation to every other Western country. Their scope has brought an element of social justice not just to a few handicapped people but to very nearly all. In this sense, they have been an unanswerable argument for public planning as opposed to private enterprise. The staffing patterns have been imaginative and creative. But if you talk now to leaders of these services, they will say that they made one important mistake. In their concern to bring mentally handicapped people the best possible help, they deliberately excluded volunteers from their planning. They denied the right to give to their normal populations and by doing so they left an essential ingredient out of their services. As social services of all kinds become more complex, more professional, as more and more people in society are acknowledged to have the right to necessary specialist help, it is a danger of which we should all be aware.

The protection of gift relationships is particularly crucial in our systems of residential care for those who have come into them precisely because society has rejected them, precisely because at some point the gift relationship has failed. We can offer mentally handicapped people, finally, very little but an endeavor to restore these relationships. We can give them drugs which may ameliorate their anguish, we can habilitate them to certain social competencies. But the most important thing we can offer them is not, in fact, technical or scientific skill. It is an assurance that the rejection which has brought them to our notice in the first place can be turned to acceptance, an assurance that we want them with us as they are. If we cannot offer this, then we are perpetrating society's rejection and condemning them to a life of continuing anguish. We must be very clear about this if our reforms in residential care are not to reecho the mistakes of the past.

We can draw a parallel between Titmuss's conclusions about the effects of a commercial blood system and the situations in the traditional institutions for the mentally handicapped which squat all over our Western countrysides. In sheerly pragmatic terms, we can say that these institutions have indeed been dangerous to the people who live in them—nearly always emotionally and too often physically. We can say that they are expensive and wasteful; what human or practical results have they achieved which a cheaper system of locally-based care for small groups of people could not have done far more effectively? In ethical terms, we can say that our residential care of the past has indeed eroded, by taking people into the hands of the specialists behind those high walls, the expression of altruism and the sense of community. We can say that the care in these institutions is indeed an expression of scientific and medical standards which have become lowered to the point of inadequate treatment at best and unethical experimentation at worst. We can say that hostility between professional and patient has become legalized to the point where not infrequently the inhabitants of these institutions have suffered outright cruelty which has been condoned by those in responsible positions. We can say that professional freedoms have been denied to the point where resignation is often the only answer to an intolerable situation and that personal freedoms have been denied to the point where the only recourse in the United States is to the courts and where, in countries which do not have a written constitution, inhabitants of the institutions have very little recourse at all.

These are some of the ills of the past which we could argue have resulted from a denial of gift relationships. It would be naive, however, to conclude that the ills come with the institutions and will automatically disappear with community residential care. Few, if any, of the originators of that old system were motivated by anything other than the most humane aspirations. Anyone who has spent time in visiting new community establishments will have recognized with something like a feeling of terror that the abuses of the old system can be reproduced exactly and perhaps even more cruelly in the relative isolation of a community setting. We are still in danger of denying the right to give.

We are in danger of denying the right, first of all, to the handicapped people themselves. Any of us knows that just as our personal qualities will flourish if they are recognized and appreciated, they will atrophy if they are disregarded. It is well known that handicapped people who have been able to take care of themselves at home will sink in institutions into a state where they are not able to perform the simplest elements of self-care simply because they are not expected to have these skills. If handicapped people continue to meet rejection of their personal qualities and abilities, however clean, new and well-staffed the setting in which they find themselves, they will continue to live down to expectations just as any of us would.

By recognizing that handicapped people can make a contribution not only to the establishment in which they are living but to the wider community and to the development of the world itself, l'Arche is recognizing their right to give, to enter into gift relationships. It recognizes their contribution to their own community through work, however simple. It recognizes their contribution to the wider community, whether through visiting elderly neighbors or helping Mother Theresa's nuns on a soup run in Calcutta. More fundamentally, however, they are seen as bringing very precious gifts in their relationships, both with individuals and with groups of people, and it is this perception which is crucial.

How to bring this perception to the staffs of our caring establishments? If it was simply a question of encouraging them to help the handicapped people help themselves, of finding ways in which they could make a contribution to the wider community, life would be simple. However, these practical details are the result, not the cause, of a basic view of people. The tragedy to me is that the basic view is there more often than not. People come into work with mentally handicapped people because they have it already or they very quickly develop it once in contact with those they are helping. The question, then, is how to sustain the perception instead of crushing it into routine and indifference?

Staff Right to Give

We have to look again at gift relationships; this time from the point of view of staff. How do we protect their right to give? In Britain, at least, a serious shortage of residential care staff in mental handicap, as in other fields, has led to a concern for training, pay, and career structures which, it is hoped, will attract more of the right sort of people into this sort of work. The approach is understandable but what it is effectively doing is crushing the right to give into a system of contracts and job descriptions. People are expected to fulfill a clearly defined role rather than to give of themselves. If this is the expectation of them, it is not surprising that it is the expectation they have of others. So staff, themselves expected to keep their charges clean and tidy (for how to define their job except in these mechanistic terms?), expect that the handicapped people will submit, in their turn, to being kept clean and tidy. The thought that these people can cope perfectly well by themselves and that being clean and tidy is hardly the essential in a sharing situation is bound to become a threat. If you do not fulfill the job specifications, after all, you are likely to be dismissed.

At l'Arche, as we have seen, the situation is quite different. The whole structure depends on a gift relationship of a very clear-cut kind. "Our houses," Jean Vanier has noted, "can only live through gratuity. If tomorrow everybody went onto standard rates for hours and salaries, our houses would collapse. This means that the director, if he is a good director, must sense whether this gratuity is growing or getting less. If he senses that it is lessening, the whole house is on the road to death. He must try to help the assistants give in a spirit of gratuity; he should have built-in ways of helping people to live in this spirit."

This is not, of course, to suggest that residential establishments immediately stop paying their staff and refuse to negotiate terms and conditions of service with them. This would clearly be ludicrous and is besides irrelevant. The fact of unpaid overtime itself is no guarantee that there will be any gift relationship at all. But it is to suggest that if our residential establishments are to provide the atmosphere of warmth and mutual respect between helpers and helped that is essential to the growth of each, ways must be found to encourage the gift relationship that comes not with unpaid overtime but with the quality of the look, the touch, the evidence of listening and understanding that comes during the hours worked.

Anyone who has visited even the worst of our run-down, overcrowded institutions on either side of the Atlantic must have been struck by the most glaring contrasts even within the drab similarity of the wards. In one, the inmates will appear more peaceful, more open and friendly. They will have, however tentatively, that flicker of community with each other and with the staff which makes the place seem somehow alive. In another, where both the staff and residents are ostensibly the same sort of people, the whole atmosphere is different. You are struck first of all not by the people but by the smell, the peeling walls, as the handicapped people either ignore you or clutch at you in a bid for human response, as the staff drag themselves wearily from their cup of coffee to show you around. In both wards, the staff are putting in the agreed union hours for the agreed union rate; but in one there is a gift relationship and in the other there is none.

If this is true of our wards, it is also true of any of our new community residential establishments. If we go into one and see first the friendly expressions on the people's faces and into another and see only the rather nice soft furnishings and ingenious space dividers, in the first there is likely to be a gift relationship and in the second there is likely to be none.

How then to encourage gift relationships for staff? It is not enough to say that some staff are good and others are not. This is an area where the management of our establishments has a very clear responsibility. For if it is true that handicapped people live up to or down to our expectations of them, this is no less true of staff. Management must start, quite simply, by acknowledging that each member of staff is not a cog in an organizational wheel but an individual with a contribution to make. It must recognize his right to give.

This means far less clear-cut expectations of staff. A chief nursing officer in a British institution for the mentally retarded not so very long ago defended the situation on a ward where young children were living in a state of almost total emotional deprivation by saying, "But we have never had a death there!" This was not her fault. She was responding to what her management had laid down as the main purpose of her job—the treatment of physical ailments and the prevention of death. Perhaps this is an extreme example; but if a member of management at whatever level criticizes a more junior member of staff for having an untidy house, without first finding out that it is untidy because the staff and residents were playing cards together instead of doing the housework, he too is in danger of promoting functional at the expense of gift relationships. If he dismisses a member of staff for not pulling his weight, he must first be very sure that he is not dismissing the man who had the most time to listen to the handicapped residents and form a relationship with them.

We need to work towards a situation where each person has the job and responsibility that suits him best and will best encourage him to give. It is a matter of being flexible in expectations of staff and trying to find the particular contribution that each one can make, even if it does not fit very clearly into a certain job description. Visitors to l'Arche communities are sometimes surprised to see that while some people appear to have too much to do altogether, others are working only part-time and still others not, in any conventional sense, at all. This is sometimes the result of bad organization and it is one of the main sources of friction among assistants. Nevertheless, at best it is the outward sign of a constant attempt to find the right job for the right person, to find what will most help him to contribute to the community. It is this constant effort which finally makes it possible for l'Arche to run as it does. Assistants are seen not in terms of possible functions they might fulfill but as people with a particular contribution to make. While the extreme flexibility of l'Arche cannot be altogether reproduced in more conventional residential establishments, there is still an important lesson for management in the way it goes about staff deployment.

There is a lesson, too, in the very nature of the staffing. L'Arche assistants are predominantly untrained and although a few have relevant professional qualifications, most are simply people who are drawn to this way of life. Professional help comes either from people who come into the communities on a sessional basis or to whom the communities turn just as any of us would turn to a doctor, dentist, or other specialist. More than this, there is a very high turnover among l'Arche assistants; a great number of them stay for about a year.

Because l'Arche believes that the quality of relationship is more important than the time put in, this system works. In sheerly practical terms, it would be hard to find many residential establishments which are more conscious of their need for specialist help, whether from the psychiatrists who come into the communities as consultants or from the range of community health and welfare services available to the normal population. The high turnover of assistants can certainly lead to difficulties in ensuring the continuity of life for the handicapped people, although there is now a growing number of people who have been with their communities from the start and a central core who are going to stay for the definable future. The pattern tends, however, to be seen as positive rather than problematical, the greatest assurance against the communities sinking into institutional apathy. The approach has something of the pragmatism which has characterized the Danish approach to staffing, where a high turnover, though certainly not as high as this, is recognized as inevitable, welcomed, and planned for.[12]

This approach to staffing seems to me to be far more realistic than one which depends on creating career structures and hoping that staff will stay long enough to enjoy them. It is by no means proven that this is the right approach to work as demanding as residential care. What is certain is that there are very many young people who would, if conditions are right, be glad to work for a year or two in our residential establishments, and that the ability to assume responsibility has very little to do with training or even experience. It is up to those responsible for the establishments to ensure, as l'Arche tries to do, that the conditions are right for each individual to make his own best contribution.

For this approach to succeed, the people at the top of the hierarchial ladder must know the people at the bottom rather better than they sometimes do now, and here again the openness of relationships in l'Arche communities and the almost complete lack of obvious hierarchies brings an important lesson. More than this, though, the very structures of the establishment must express a belief that every staff member has a contribution to make, and this means searching for ways in which the less obvious, but nevertheless powerful, hierarchies can be modified into structures of democracy.

Democratizing Hierarchies

The hierarchies of l'Arche tend to become blurred by the extraordinary power and persuasiveness of Jean Vanier himself, and Wolfensberger is far from being the only person, inside or out of the organization, to point a warning finger at what traditionally happens when a very strong leader disappears. Nevertheless, for a structure of its size, the Federation of l'Arche is able to leave its component parts a quite remarkable degree of autonomy. Each community is able to interpret the basic tenets of the organization in its own way, just as each individual house which makes up a community has freedom to run itself as seems best to the community of people living in it. It is a situation of trust which can on occasion misfire badly, but which far more often is one of the chief enablers of growth.

While again, more conventional residential care may not be able to draw direct analogies from l'Arche's situation, it can still learn the principle from it. The best of our traditional institutions are very often the ones where staff know that they have autonomy to work out their own ways of going about things and that they have the support to make their ideas work. The worst ones are those in which initiatives from the people most involved, the front-line staff, have been overridden by a central policy. The same is true of community residential establishments where directors and staff feel either that they have the support and encouragement of their management or where they feel crushed by a board which will constantly be dropping in to criticize and modify. In the first, gift relationships between staff and between them and the handicapped residents are likely to grow; in the second, they are likely to atrophy into observations of the letter of the law.

This is one way of breaking down hierarchy. In l'Arche communities, particularly the larger ones, there is also a constant searching for structures of consultation and shared decision-making. At Trosly, for instance, there is a proliferation of small committees which study different aspects of the community's life. There is an annual working weekend at which policy directions for the next year are discussed and to which every assistant may contribute. There are frequent revisions of the structure of the governing council in an attempt to make it more genuinely representative of the feelings of the community. The forms of democracy towards which this particular community is struggling are those which seem to suit it best, and they are not too relevant to the main point, which is that this is work which every residential establishment, whether large or small, as indeed every industrial as well as caring concern, should be doing for itself.

L'Arche communities are still a long way from realizing the ideal of the therapeutic community as one in which every staff member is recognized as having as relevant a voice in the development of the whole as the most senior professional worker, and in which each patient or resident is equally seen as having a no less essential contribution to make. L'Arche has not yet the skill to find ways in which its handicapped members can be incorporated into its decision-making processes. But if l'Arche still has much to learn from the experiments in therapeutic communities scattered through institutions in Britain, North America, and elsewhere,[13] it has at least progressed further along this road than many other residential organizations for mentally handicapped people. If more traditional organizations look at l'Arche and say that this has been possible because of the unusually high proportion of assistants to handicapped people, l'Arche can remember its own shaky beginnings and ask what it is that now attracts assistants in such numbers.

Community Relations

If staff must find ways of encouraging gift relationships within their establishments, they will at best find support from the same sort of relationships between themselves and the wider community. More often, as we all know, the caring community, on whom so many of our reforming hopes depend if we are not simply to recreate ghettos for the rejected, seems to care only for its own property values. The relationship between the wider community and an institution for the mentally handicapped, of whatever type, can too often seem purely the functional one between people who pay for care on one hand and people who struggle to maintain the standards demanded by this financial support on the other. I have already suggested that the way our public caring systems are developing is bringing a real danger of the erosion of gift relationships between the community and its members who need help. What are we doing to ensure that these relationships are encouraged rather than squashed in the particular field of residential care for mentally handicapped people?

The answer must be "not nearly enough." We must accept, as a start, that people are afraid. They are afraid of the funny folk who have moved in next door or who, worse still, live in that place on the outskirts of town. It is understandable that they should be afraid, and no rational explanation will overrule the very deepseated fears that handicapped people arouse in us all and that only those of us who are lucky enough to have fairly constant contact with them have the chance to explore and come to terms with. People may not, at a conscious level, see the handicapped person as a reminder of their own essential weaknesses; they may not even think that that same person is likely to attack them or rape their daughter. They will, however, be rather more consciously afraid that these people are going to be useless, that they are dependent in a way which makes any normal human relationship with them impossible, that any relationship would be so demanding that it is best not entered into except by people trained to cope.

And then what happens? They see handicapped people who, themselves seen as receivers rather than givers, appear indeed to be incapable of normal relationships. They see staff who, their own relationship with the handicapped people defined in terms of job description, confirm that you have to be a specialist to do this kind of work. There is no place for normal neighborliness here.

It is all too expectedly frightening. This is, of course, a stereotype of roles and reactions. But we are faced with a situation where it is precisely stereotyped views of the handicapped person that we have to try to dispel.

We have already seen the ways in which l'Arche communities go about doing this. Here are collections of people, some of whom have rather obvious handicaps, but all of whom evidently get a tremendous amount of joy and satisfaction from each other's company. No one wears a white coat or has a title which indicates they have been trained to enjoy the company of handicapped people. It is really very easy to join in a l'Arche open house and really not difficult at all to enjoy it. L'Arche communities encourage gift relationships between themselves and the outside community, not by waiting for some act of neighborliness on the part of their neighbors, but by offering their own joy and perception of the handicapped person.

"Far from withdrawing from society," says the Charter, "we want to act as leaven in the dough. We want to try to make our own contribution to transforming our society from one that puts value on individualism, intelligence, and technical skill, and on the search for pleasure, riches, and power, to one that comes closer to the values of the Gospel. We want to help society find hope." And it does this not by asking for functional gifts of money, cookies, and clothing but by offering and asking in return gift relationships of friendship and support. So the reciprocal gift relationship between l'Arche and the wider community is built up, a relationship which is certainly not without its tensions, but which is no less valuable for that.

"People hear about Daybreak, and they come in order to offer their presence and skills. Almost invariably, however, they find that while they are offering themselves, they are also receiving something from the men and women who live here. They cannot help but be moved when they are met by the warm welcome of our men and women, by their smiles and confidence. Free from the bonds of conventional society which so often sees people as functions, free of the barriers which prevent human encounter, it is easy for them to establish conversation and relationships very rapidly. This quality of welcome which comes from the residents permeates the spirit of the house; it would be ridiculous to welcome the handicapped and at the same time not to be open to those who wish to visit, to meet, or to work with them." Steve Newroth's comments about Daybreak apply equally to any l'Arche community.

We are back to the gift relationship offered by the handicapped people themselves and to l'Arche's recognition of this as the essential ingredient in a network of gift relationships which is woven between handicapped people, assistants, and the wider community, in which all three give and receive as the gift grown in reciprocity.

It is this understanding of gift relationships which is l'Arche's essential contribution to residential care for mentally handicapped people. It is a contribution which is relevant in all our caring establishments, wherever they are and whoever sets them up and sustains them. It is a challenge, quite simply, to put our faith in people more than in organization, to recognize that however much we work on the second, it will fail unless we have found the ways to welcome and encourage the first.

It is a challenge which is not very comfortable, because it leads us to relationships which are not so easily categorized as those on which residential care is theoretically built. It is even rather frightening because we do not know where these relationships will lead us. It is frightening because it leads us to recognize just how fragile even the best of our organizational structures are, how impossible it is to find the people-proof system which will guarantee us clear consciences.

And at the same time, and for just these reasons, l'Arche's challenge is the most exciting and heartening one we have today. In a world increasingly caught up in a technology and specialization which seems at the same time to carry both our destruction and the means of our survival, it is ridiculous that something as simple, as inexpert, as fragile as l'Arche should exist at all. That is should exist and be growing in the way it is turns the ridiculous into something like hope. On the current balance sheets, love is usually put down as one of the scarcest of our scarce resources. Perhaps what we should be doing is listening and learning and finding the ways for it to express itself. We might then discover that it is a good deal less scarce than we have given it credit for.

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Part VI: Not an End, But a Beginning

26. Toward Further Change

Robert Kugel and Ann Shearer

Looking at the future is both exhilarating and frightening. On one hand, we have the expectation that our attempts to understand the past must lead somehow to greater fulfillment. On the other, we know that no one can accurately predict the multitude of factors which will affect our direction. This is as true of our services for mentally retarded people as it is of any other aspect of the way we organize our societies.

But even though we cannot accurately predict where we are going, it nevertheless seems important to try to grasp the trends of our times and the possibilities before us. It is important because we are living, perhaps as never so clearly before, through a time of choice in the way we regard the people we define as mentally retarded and the way this regard is reflected in services.

The late 1960s and the early 1970s have been a period of optimism. Earlier indications of how mentally retarded people can be helped, strengthhened by a coherent philosophy of care, have grown into new approaches. We have seen a revulsion against the large institutions and we seem to be reaching toward workable alternatives. We have the plans; we even have the services on the ground.

But now we are discovering that it is not as simple as we had hoped. We are finding out, in very practical and day-to-day ways, exactly how complicated it is to build patterns of support for mentally retarded people living in the community. We are discovering that individual people do not fit tidily into our overall schemes for change. At the beginning of this book, we asked what was being offered to particular "problem" groups of mentally retarded people; the answer must be not nearly enough.

At the same time, we are living through a very uncertain economic situation. The people who have led new programs have been aware that these programs would very likely not have developed if it had not been for the relative affluence of the West during the 1950s and 1960s. We must all now ask ourselves whether we can continue to develop as we have done. Will the money be there to develop new patterns along present lines or will it seem cheaper in the short term—and who is looking at long-term investment these days?—simply to shore up the old? Will rising unemployment mean that fewer handicapped people can hope for work on the open market? Will lack of jobs, in turn, mean that some people now living in the community have to move to an institutional setting?

In this situation, there is a danger that the past decade will come to seem something of an optimistic intermission in the pattern of care which has been developed over the last century. We have seen such optimistic phases before, and certainly individuals have benefited from them. But at the same time, they have left the old philosophies, of which the neglected large institution is the symbol, barely dented. We are now at a time when, once again, we could settle for amelioration rather than for fundamental change.

Our other alternative is to seize the new philosophies and emerging patterns and develop them beyond the present reforms in residential care to a coherent pattern of services to the retarded person in his own community. The challenge now is to make the long-term investment in care and social development which will give life to our current rhetoric of "rights" and "community care."

The challenge is not comfortable. It means accepting the full presence of the handicapped person as one of us and so, ultimately, a reminder of our own frailty. It means living more nearly with our failures to provide people with the help they need. It is one aspect, finally, of the choice that increasingly faces our societies between finding ways of accepting the diversity of human nature and rejecting some sections of our communities in the search for an elusive, comfortable "norm."

We have already seen what is happening to our inner-city areas and to life in our cities as a result of our pursuit of the second choice. We are beginning on the broader canvas to see what is happening to relationships between the countries of the West and the developing world as the result of that same pursuit. Finding ways of accepting and living together with those we have rejected and exploited in the past as "handicapped" and "different" is now becoming more than an expression of humanitarian concern; it is becoming a matter of survival.

So the challenge now is to develop our reforms in residential care for mentally retarded people within a broad context of finding ways of bringing them more nearly into the community which is theirs and also our own. And while the challenge is primarily to help them reach fulfillment, it is all of us who will gain.

Here then are some of the areas which it seems to us must be tackled if the current phase of reform is to develop into future change for mentally retarded people and for the communities to which they, and all of us, belong.

Prevention

"An ounce of prevention is worth a pound of cure." So we say, but what we do suggests that we simply do not believe this.

Some of the most extraordinary advances in the health of the people have been achieved through preventive measures. Proper sewage disposal and clean water and milk supplies have all but eliminated typhoid fever in many parts of the world. Poliomyelitis has been eliminated as a scourge as the result of immunization. Despite these obvious examples, much of public attention is generally focused on the more dramatic achievements of contemporary medicine, such as open heart surgery or kidney dialysis.

In the field of mental retardation we have long been accustomed to dealing with situations after the fact. The measures which can be used in prevention are few and the treatments, which are specific, are often still in their early stages. The early identification and dietary treatment of phenylketonuria offer an example of prevention which, however, affects only a tiny proportion of the people we know as mentally retarded.

There are, however, possibilities of prevention on a far wider scale. The tragedies of the abandoned family and the mentally retarded "criminal" and the anguish of families with a retarded member could all be significantly relieved if we started to take prevention seriously.

The Abandoned Family

Although one of the definitions of a healthy society is that it wants and values its members, there are many people now in institutions for the retarded largely because they and their families were abandoned by society. Many of these people are the victims of the endless chain of debilitating povery and some of them will be classified as having "familial mental retardation." There seems little likelihood that this group of people will change in either character or number unless we make a serious commitment to prevention. But the attempts to attack poverty which were launched in the mid-sixties in the United States have now largely been abandoned, even though in complex cities, like Copenhagen and Stockholm, the problems of familial mental retardation seemed to be virtually eliminated as the result of social reform and action in Denmark and Sweden over the past 30 years.

So we have the choice. Either we accept that which we now call "familial mental retardation," with all its associated tragedies, or we launch the massive and sustained programs of social reform which will not only alleviate these tragedies but ultimately increase the health of society as a whole.

The President's Committee on Mental Retardation in 1972 had this aspect of prevention very much in mind when they urged that the necessary commitments be made to reduce mental retardation by one-half by the year 2000. We believe that this is feasible. There has already been a great deal of discussion and demonstration on this subject. But if the impact on the lives of large sections of the population is to be significant, then a serious commitment of energy and resources must be made.

The Mentally Retarded "Criminal"

It is estimated that the number of mentally retarded people living in penal institutions in the USA is as high as 5–10 percent. Although the situation is always complicated, many people with mild mental retardation are lured into various types of antisocial behavior—larceny, vandalism, and the like—in part because of their inability to understand the implications of such behavior. Some of them come from the impoverished homes found in our medium and large-sized cities, and partly because of the incompleteness and inadequacy of social planning, they can slip into a life of petty crime.

Once they are judged to have committed a criminal act and have been sent to a penal institution, they often simply do not receive appropriate help. Once released from the institution, they once again find themselves in the same situation.

The number of people who return to penal institutions again is high although we do not have exact information about this form of recidivism. Again, these tragedies could be prevented in much the same way as those of the abandoned family. We need massive efforts to rehabilitate the low-income sections of our cities and to offer more to those who live in them, particularly adolescents. Unless this massive social reform takes place, and with it significant reform in rehabilitation in institutions, people will go on ending up in penal institutions in the same numbers as they do now.

The Anguish of Families

Although there is no way to "immunize" against anguish, there certainly are some ways in which it can be lessened. In 1975 there are still parents being advised by physicians, social workers, clergymen, and friends to place their child in a residential situation with the expectation that he or she will be there for life. There must be fewer situations where parents who care for their child are advised and encouraged to "forget about your job" or "do the best you can by sending him away." The enormous guilt feelings which many people develop when given such advice must be understood.

If their anguish is to be lessened and at best turned to the joy they would experience with any other child, parents and families must get the support which will sustain them through the many difficult moments they will experience. This will mean sensitive counselling from the time the child's handicap is known, from both well-informed professionals and, as valuable, from other parents. It will mean continuing support and guidance in the family's own home as the child develops. It will mean offering parents the "time off" from their child which any other parent needs. It will mean close liaison between professionals at all stages, particularly as the child enters school.

We know how far we are from providing many of these essential supports to families with a handicapped child. But again we have the choice. Either we can start now to make a far greater and more sensitive investment in supporting these families or we can continue to tolerate a situation of preventable anguish. What we need now is a coalition for all those concerned about handicapped children to ensure that, however a child or a family is labelled, each gets the service which is particular to their needs.

If this is the alternative we choose, society as a whole will benefit. People often ask why some of the services available to handicapped children, like day-care centers, vocational training programs, improved education are not also more available for the "normal" child. The answer is disarmingly simple: the same kinds of programs should be made available but parents of normal children have not yet combined forces in a way which puts enough pressure on legislative bodies and government officials to bring about the necessary changes in funding. It is when we have a powerful coalition of those concerned with all handicapped children that there will develop a far greater interest in the needs of children in general and this can only benefit us all.

Residential Care

It is within this context of prevention that we must, in the future, learn to look at residential care. Too often in the past, the sheer and immediate horror of our large institutions has deflected our thinking and we have put the issue of residential care in the center of our concerns instead of seeing it as simply part of a spectrum of services. We have been preoccupied for so long with the questions of "large or small" and "centralized or decentralized" that we have forgotten to ask "why." Even now there is a tendency to see residential care as the center of our community planning—a building, after all, is so much more noticeable an evidence of our concern than, say, a program of home education for young children and their parents.

We must be careful, however, that it is not simply the present trends in the economic situation which give us the impetus to reorder our priorities. Certainly it is cheaper for handicapped people to live at home with their own families than it is for them to live in residential care, given the same range of educational, therapeutic, and other services in each case. Their own home will also be the best place for nearly all children to be. But we must be careful to ensure that for each individual we do the best and not simply the cheapest; it is no more than a bonus if the two happen to coincide.

The best, for some children and very many adult retarded people, will continue to include residential care in some form or another. We are already beginning to see the development of the wide range of homes, apartments, foster placements, and respite caring situations that "residential care" should mean in the future. What we cannot say and what indeed we should try to stop ourselves from asking is exactly what the demand for residential care will be in the future. It could be that supportive services to families and individuals will lessen the demand; it could be that as the choice in residential care gets wider, demand for this service rises. What we need is a service which is flexible enough to respond to these changing needs.

What we can more certainly say is that unless we start tackling preventive services with all the commitment we can muster, not only will the demands for the new types of residential care continue, but we will have to come to terms with the continued existence of institutions which few people would today consider fit places for human habitation.

Unless we tackle the problems of deprivation, abandoned families will continue to have no choice but to accept the only institutional provision available to them; unless we offer sensitive services to the particular problems of the mentally retarded people who get into trouble with the law, they will end up in some penal institution or another; unless we are committed to supporting families, the lesser anguish for some will continue to be an institutional placement for their child. We cannot tell these people all to wait until the new pattern of community-based residential care is on the ground and working; their problems are intolerable now.

But even if the new patterns of residential care were more widely available, it would very often be the wrong answer for these people now in need. We must be clear that while residential care will be a good and necessary component in services for some people, it will never be more than a second-best solution and even an admission of society's failure for many others. Patterns are changing in residential care and that is good. But our efforts must not stop there.

How to Sustain Change?

Much of this book is a consideration of how change comes about, an attempt to tease out the different people and organizations who have helped us to get where we are today. Their help is going to be every bit as much needed in the future as it has been in the past. A few exemplary services do not make a whole new pattern of care nor, without continued, patient, and thoughtful pressure from the many people and organizations who have made contributions so far, will they ever. Times of economic stringency are notoriously bad times in which to be in any way handicapped or to need social services; the efforts of all those who have acted as advocates in the past, however obliquely, will still be essential if our patterns of care are to change further.

But we are talking now of changes not simply in quantity of services on the ground, but of quality. We are talking of changes which will certainly, first and foremost, affect those we now call mentally retarded and those close to them but will also affect the very way in which we organize our societies. An attack on the problem we now label "familial mental retardation" will inevitably mean very great changes in the life of our cities. A wholehearted commitment to support for families will inevitably lead to a rising expectation for all the nation's children. The benefits of change for mentally retarded people, as we have said, are benefits for us all.

But if these changes are to be achieved, they will demand a new sort of commitment. We have already suggested that a proper system of support for families will come from the work of a coalition of all those concerned with handicapped children, whatever the label we attach to the handicap. It is through cooperative efforts like this that we will get beyond the patterns we have now. We have already, for instance, seen the quite remarkable difference in the way handicapped people are perceived in the United States as a result of the involvement of the legal profession in their situation. It is by seeking the cooperation of people outside the traditional range of those concerned with retarded people that further change will come.

Certainly it will not always be easy; certainly those concerned with retarded people will often want to feel that the cooperation is on their terms. We are already seeing some of the ambivalences of the situation. On the one hand, there is a growing demand for integrated schools which offer mentally handicapped children their chance to share the life of their peers—and which, as important, allow "normal" children to meet "different" ones.

One the other hand, we are learning a great deal about the need for more and more boards specifically concerned with the coordination of services for retarded people as they seem in danger of being swamped in the generic demands of other groups. We will no doubt continue to move in these two directions at once for some time to come. But the perspective must be clear: the struggle to gain justice for retarded people is, finally, the struggle to make society just for all its citizens.

This, then, is the context within which future change will come, within which we will get beyond changing patterns in residential care to changing patterns of life for mentally retarded people. And for these changes to be sensitive to their needs, we must bring those most closely concerned more nearly into our planning.

The contribution of parents who do not sit on committees and attend international congresses and of the staff who do not give speeches or contribute to theories of care is also part of the whole. We must find ways to listen to them, for their contribution is no less vital than the more easily measurable ones.

And finally, here are the handicapped people themselves. It is around them, after all, that volumes like this one are put together and meetings are held and services are constructed. It is they who have had to bear the real anguish of society's rejection and for whom those large, neglected institutions have been not just a symbol of a system but the only home they knew. It is they, finally, who will have to live most nearly with the changing patterns of the future.

If we who concern ourselves with their situation cannot grow to listen to them, to value them, and to recognize their gifts, what hope will there be of change that is any more than the old rejections in dressed-up new guises? They have been very patient with our follies in the past. They will probably continue to be so in the future, for their gifts are not generally those of militancy. Perhaps we can now begin to work with the people we call retarded and not simply for them. That, in the end, is what further change will be about.

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